

## ***Press Release***

***for immediate release***

***8 July, 2005***

### **Dementia our Cinderella disease, says author**

Dementia is one of the most common but worst treated medical conditions of our time, Marion Shoard, the author of *A Survival Guide to Later Life*, told a Skipton audience yesterday (Thursday, July 7). She said a transformation of both treatment and awareness was urgently required. She pointed out that a new education programme by the Craven branch of the Alzheimer's Society launched yesterday was blazing a trail in support for people with dementia and the family and friends who care for them.

Marion Shoard, who first became interested in help for elderly people when her mother developed dementia seven years ago, was the first speaker at a Carer Support series of lectures and discussions which will take place weekly until September 22nd, organised by the Craven branch of the Alzheimer's Society. Dementia is a generic term for progressive loss of mental capacity in many areas including memory, language, the ability to reason and the capacity to cope with the activities of daily life from, in the early stages, managing money to, later, feeding oneself. It is highly age-related, with more than one fifth of people over 80 falling victim. The most frequent cause is Alzheimer's disease – characterised by changes in the configuration of nerve cells in the brain. The second main cause, known as multi-infarct dementia, results from many imperceptible strokes which kill off brain tissue as a result of an unhealthy cardiovascular system. A different sort of change in brain cell configuration also of unknown cause is the third main reason for people developing dementia and is known as Lewy body dementia.

## **Ignorance**

Miss Shoard said: "More than 700,000 people in the UK have dementia – that is four times the number with breast cancer, for example - and this number is expected to rise to 850,000 by 2010. Yet many ordinary people have far less understanding of the main symptoms, let alone the principal effects on the individual, of dementia compared with other less widespread medical conditions.

"The nature and effects of dementia are far more difficult to explain to non-sufferers than other medical conditions such as skin cancer or a broken leg for several reasons. Firstly, the absence of any known cause rules out an-easy-to-understand cause and effect, as is the case with smoking- related diseases. Secondly, dementia produces a range of effects on behaviour and capacity, and this variation is compounded by wide variations between individuals both in the parts of the brain affected, the effects of those changes and the rate of progression of the condition. What makes dementia thirdly and almost uniquely challenging however is the fact that it is often accompanied by a very significant loss of the ability to communicate. This means that sufferers cannot appear on television explaining what dementia means to them on a daily basis.

"The media does little to help. Dementia is rarely discussed on TV chat shows, portrayed in soap operas or explored in the health pages of magazines and newspapers. Where it is depicted, as in the recent film Iris or the television drama about elder abuse, Dad, it is done so in a partial, sanitised way which leaves the viewer with little real understanding of what it means to have the condition, let alone how those with dementia should best be cared for.

"Often people are not only ignorant but they do not wish to know about dementia. It carries the stigma of all mental illness in our society. But because it is very largely a condition of old age, dementia has to cope with the additional handicap of association with a group in society often regarded as having little worth compared with younger people.

## **Care**

"All this influences the type of care provided. People with dementia need a great deal of help. Their ability to receive it is often compromised by the decline of their ability to communicate. Frequently they cannot convey to others their wishes, likes and dislikes, concerns, or symptoms of other, unrelated medical conditions. They are vulnerable to others claiming to know what is best for them and what they would like. And because their word often cannot be relied upon so they cannot reliably report what has transpired, people with dementia are highly vulnerable to abuse and neglect.

"People with dementia have to cope with a health service which pays them scant regard. People experiencing very severe dementia used to be looked after by the health service in long-stay psycho-geriatric wards. But successive governments since 1970 have taken away nearly 60 per cent of these beds, although the numbers of people needing them has increased substantially. Think what the outcry would be if the beds involved were for maternity cases.

"Those who fail to secure one of the few remaining NHS beds as well as others less seriously ill are usually looked after at home by family carers or in care homes.

"The care people with dementia receive in care homes varies massively. Problems in care homes include inadequate numbers of underpaid, undertrained staff, minimal regulation and lack of funding from central government to the local authorities which pick up most of the bills.

Miss Shoard went on: "There will never be sufficient staff in care homes or even NHS long-stay establishments to give people with dementia all the one-to-one support they need. Relatives and other visitors should be encouraged and supported to a far greater extent to give this help. Infrequent visitors need education about dementia too. They need to be encouraged to enter into the world the person with the condition is inhabiting now, rather than seeing them only in terms of the role they once played as father, employer or friend."

### ***The plight of carers***

Many people with dementia who do not live in care homes are looked after by unpaid carers – family or friends in their own or the relative's house. "As a group, carers save the health service a massive amount of money yet their needs are frequently overlooked", Miss Shoard said.

She continued: "We need a charter for carers guaranteeing them better services, more money and proper training.

"First, they need far better support services, not least time off from their caring role. Carers are entitled to assessments of their needs as carers but these assessments by social services departments, and, more importantly, the services provided as a result, are extremely patchy. The carer of an elderly person with dementia might be given help for only three hours a week in one area, while assistance might be provided most nights in another.

"The fault is not only local councils': the government's target for councils is only that they should assess 40 per cent of the carers in their areas. Yet these carers may have to cope with a person who needs help day and night with dressing, washing, feeding, using the lavatory, not to speak of one-to-one reassurance. Or the person with dementia may be mobile and strong and insist on going out in the middle of the night after presenting challenging behaviour all day.

"Carers are performing a vital public service in looking after partners, fathers, mothers, and other relatives with dementia. They are de facto nurses, care assistants and counsellors and more besides, all rolled into one. If the job were employment in the normal sense, they would be entitled to recognition and respect, a wage based on a minimum hourly payment, not to speak of two full days off for every five days they worked.

"We need far more cash passing from government to councils, ring-fenced so that it goes to carers, so that they can receive the breaks from caring and the support services they need without these making massive inroads into carers' own finances, as happens at the moment.

"Also, carers should themselves receive higher payments from the state. Carer's Allowance is not a large sum. To add insult to injury, if a carer is receiving the

## Marion Shoard:

Writer | Broadcaster | Lecturer  
www.marionshoard.co.uk

state retirement pension, then because this is larger than Carer's Allowance, no Allowance is paid.

"Such training as carers receive varies enormously. People with dementia often have other conditions as well. Their carers deserve to be offered a fortnight's free training before they take on caring and one-week's annual training thereafter. This would not only help ensure that they provide good care, but also that they learned how to care without damaging their own health.

"The Carer Support Programme of the Craven branch of the Alzheimer's Society, which I have great pleasure in launching today, represents a pioneering step in training and education for the carers of people with dementia. I wish it every success."

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### ***Notes to editors***

The meeting at which Marion Shoard spoke took place at The Friends Meeting House, The Ginnel, Newmarket Street, Skipton. Further meetings of the Carer Support programme will be held on Wednesdays at the same location throughout July, August and until September 22. Subjects for future meetings include nutrition and hygiene, power of attorney, communication with people with dementia and the role of community psychiatric nurses.

If you would like further information about the support programme or about the other activities of the Craven branch of the Alzheimer's Society, please telephone 01756 799971.

Miss Shoard can be reached on 07743 534 443.

Marion Shoard became interested in dementia when her mother developed the condition seven years ago. As a result of this interest, Miss Shoard wrote her book *A Survival Guide to Later Life* (Constable and Robinson, 2004). Her personal story of involvement with dementia is set out in the attached article from *The Sunday Telegraph*. The table of contents of her *Survival Guide* and extracts of reviews are also appended.