

**MINUTE OF QUESTION AND ANSWER SESSION AT THE ADULT
SERVICES SCRUTINY COMMITTEE ON 27 APRIL 2010**

**50/10 PROGRESS UPDATE ON THE DELIVERY OF THE NATIONAL
DEMENTIA STRATEGY**

(Agenda No. 9)

The Director for Social & Community Services, together with Ms Varsha Raja (Assistant Head of Adult Services), Mr Duncan Saunders (Service Development Manager – Older People’s Mental Health – NHS Oxfordshire) and Ms Marie Seaton (Head of Joint Commissioning – Older People – Oxfordshire County Council and NHS Oxfordshire), attended for this item in order to update the Committee on progress and to answer Members’ questions. They were accompanied by the Cabinet Member for Adult Services.

Mrs Meg Barbour (ex carer) also attended for this item in order to share her personal experiences with the Committee.

The Committee had before it a report on progress (AS9) which covered Oxfordshire’s approach and progress to date in terms of improved quality of life, early diagnosis and complex care, early onset dementia, improved information provision for carers and people with dementia and cross cutting areas of work.

Mrs Barbour made the following points:

- her husband had died five years ago. He had been very well educated and had worked in the Department of Nuclear Physics at Oxford University. They had four children together and he had run a Cub Scouts pack;
- he had retired at age sixty four and the following year the family were told that he had possible dementia. It is not possible to recover from dementia, and prospects for the person’s carer are quite sad;
- at the time of diagnosis people didn’t talk about it. She had to search for the information as there was not much information available;
- Mr Barbour never accepted the diagnosis and thought that he was fine;
- early diagnosis is very important because you have to get the person’s consent to manage their affairs whilst they still have the mental capacity to give it;
- a diagnosis of dementia is very isolating. It is easy to feel that you are the only person in that situation;
- help for the carer of the person with dementia is very important. She had received assistance from a “flexible carer” from Age Concern once a week and a support worker from the Alzheimer’s Society. She had also received great support and assistance from a carer’s support group;
- she had taken her husband to her WI group. He was a very private man and would not have wished to go when well, but did not mind at

that stage. As time went on she had to stop taking him out and apart from a day centre that he went to twice a week she was with him constantly. She had found respite support very important;

- she was very excited to be involved in the implementation of the new dementia strategy.

A selection of the Committee's questions to Mrs Barbour, together with her responses, is given below:

- **Did you have a problem obtaining an early diagnosis?**

Obtaining a diagnosis at a GP surgery can be a big problem. She was lucky in terms of GP awareness, as one of the doctors at their surgery had suffered from dementia. She was quickly sent to a memory clinic at the Radcliffe Infirmary to obtain a diagnosis for her husband. It was also recommended that they participate in a dementia research project called OPTIMA (the Oxford Project To Investigate Memory & Ageing) and they did this until her husband died. They regularly tested and questioned her husband while he was alive, then they received his brain for research after his death.

However, GPs often seem to feel that there is no point in diagnosing dementia because they feel that nothing can be done.

- **Was telecare available at that point in time? If not, would it have helped?**

They didn't know much about telecare in those days. Telecare can be useful where the carer has the mental ability to use it. If someone with dementia was trying to use it without a carer then this would be problematic.

- **Do you agree that respite care is essential for carers of people with Dementia?**

Yes. Mrs Barbour made the following points:

- she organised lunches for people with dementia and the people that care for them;
- the dementia support groups required only a cup of tea and a facilitator and sometimes a speaker, but were not expensive. They were very useful because carers needed to know where to go for information and where to get help;
- she was also a trustee at Daybreak Oxford which provides specialist day care for dementia sufferers;
- her husband finally went into a nursing home for the year before he died, because she was unable to cope physically with the demands of looking after him;
- in the early stages of dementia people often get lost and forget where they are going, for example, if they are driving. However,

it is still often possible to have a “normal” conversation with them. Just an hour respite for a carer is of huge benefit to them.

- **How did you find the availability of respite care?**

Mrs Barbour stated that she had needed daily respite care to begin with. The care had been available and she had been able to obtain it. She added that home support provided by social services was inadequate because a fifteen minute visit was insufficient. Toileting, washing and dressing a person with dementia could be very time consuming.

- **Do you think that the medical model in relation to whether or not to diagnose dementia is inappropriate?**

Mrs Barbour stated that it was important that early diagnoses be given for the sake of the carers. Dementia could not be cured with pills. The carer was hanging in on there and still had a life. Their GP would probably have to treat them for depression, ill health and possibly deal with their suicide unless they were kind enough to refer them to someone. The carer would suffer if the GP did not give a diagnosis.

Ms Raja reminded the Committee that the National Dementia Strategy was a five year plan that the authority was required to have in place. A joint team comprising officers from the Council and NHS Oxfordshire was looking to implement it and many of the issues cut across both organisations. A small officer working group had been set up in Oxfordshire since the publication of the strategy and Mrs Barbour and Ms Ruiz had helped to shape Oxfordshire’s plan. There was still much to be done, for example, services were still not fit for purpose and care home staff had not all received training in dementia skills and awareness.

Ms Raja then updated the Committee in addition to the information provided in report AS9. Key points are given below:

- two contracts had just been awarded for outcome focused home support. To change the whole of the home support system at once might destabilise the market, therefore it was being reconfigured incrementally;
- intensive training support for carers was very important. Officers were taking forward a learning exercise which was receiving national attention;
- officers were also looking at technology and had already introduced certain elements, for example, the Just Checking and Wandering technology which triggers alarm bells to the carer if a person is wandering;
- in terms of memory services there were still insufficient numbers of people receiving a diagnosis. It was not possible to receive appropriate support prior to receiving a diagnosis.

Mr Saunders reported that NHS Oxfordshire was leading on the early diagnosis and complex care and early onset dementia work streams. Dementia for the under sixty-five's was still a rare condition and the biggest risk in terms of developing dementia was age. Increasing the early diagnosis of dementia was very important as currently two thirds of people with dementia had not received a diagnosis. In terms of reviewing the existing memory services officers were looking to create a single pathway of care with a single point of access as there were currently no clear guidelines as to why people should choose one model of service over the other and no consistency of service. Officers were also looking at the provision of support post diagnosis, which - as Mrs Barbour had made very clear - was devastating. It was important that people must be provided with access to that support regardless of where they had received the diagnosis.

The Committee then asked the officers a number of questions, a selection of which, together with the officers' responses, is given below:

- **Was there sufficient money to action the plans arising from the national dementia strategy and were any of these funds under threat?**

The Director for Social & Community Services stated that there had to be money to address dementia as improving the diagnosis and treatment of dementia - including improved information for people with dementia and their carers - would save money in the long term, as dementia was a key reason for people going into residential and nursing care and was half of Adult Social Care's current expenditure. He added that there was also a moral duty to address this issue.

- **Where were the three Dementia Advisors located?**

Initially in four GP surgeries: Banbury Hightown, Abingdon Malthouse, Shipton under Wychwood and Kennington. All of the above surgeries had expressed an interest in dementia. Due to insufficient numbers of referrals Kidlington, Islip and Bicester had also been identified.

- **Was it correct that keeping people with dementia at home was better for them than going into a nursing or residential home and was there also a deficit in the number of beds for people with dementia?**

A residential or nursing home was a new setting for a person with dementia and therefore Extra Care Housing might be more appropriate. It was true that staying at home provided an improved quality of life for the person with dementia than a residential or nursing home and was a more cost effective means of supporting people. The Carers' Support Project was an important part of this and it was hoped that four hundred carers could be supported. There were a significant number of contracted beds with the Order of St John.

- **Were people with dementia going into residential or nursing homes because the carer could not cope any more?**

Mrs Barbour stated that this was often the case. She added that in her view the optimum way forward was for day care to be provided, then respite care, then the possibility of long term nursing/residential care if the situation worsened. If this care could be provided from the same building this would be fantastic. Sheltered housing would also be good.

- **Did the Strategy look at helping the carer to deal with bereavement and get back into work if they needed to?**

This was the most important area of support in the Strategy. Mrs Barbour and Ms Ruiz's caring responsibilities had come to an end and they were both helping to influence the strategy. Officers were trying to visit a number of carers support groups attended by carers and people whose caring responsibilities had come to an end and they looked at rebuilding their social networks. There were four elements of support to the carer's package from which carers could pick and chose. This included giving people psychological, emotional and physical tools such as a direct payment of £150 to help people to take up alternative therapies or adult learning courses to aid stress relief, and as the training courses for carers were delivered informal social networks often developed as a result where people helped each other. The Directorate also asked a significant number of carers what they needed (c 400), which helped to shape services.

- **This assistance was costly. Nationally PCTs had been allocated £60m in the first year and £90m in the following year. Had Oxfordshire PCT received any of this money and how was it being used?**

Ms Seaton stated that there was over £2.7m in the CHC budget which was specifically focused around dementia. NHS Oxfordshire had invested £116,000 this financial year for developments around dementia and no financial savings from this area were expected for this financial year. It was expected that this amount of money would be invested in future years.

- **Would the savings requirement for NHS Oxfordshire be increasing the next financial year?**

In relation to the NHS operating framework there would be no area that remained untouched but NHS Oxfordshire was giving a very strong commitment to this area.

The Director for Social & Community Services reminded the Committee that savings would be generated by developing the types of services set out in report AS9.

- **The apparent loss in day care with day hospitals going was a concern.**

The Directorate had carried out a great deal of consultation with carers about this. Carers had said that they wanted there to be a range of options in place such as day hospitals, day services and care homes. They also wanted respite care to be provided in their own homes.

Care homes also provided carers with breaks for a short period of time, but it could be difficult coping with the person with dementia once they were back home due to their disorientation and behavioural changes.

Officers had identified areas where respite was not being heavily used and had decommissioned this and provided a direct payment to people instead which gave them more flexibility, choice and control. For example, they could use the money to arrange a short holiday.

Following the question and answer session the Committee then **AGREED** to:

- thank Mrs Barbour for sharing her moving and frank personal experiences with them;
- thank officers for their contribution;
- keep progress on the National Dementia Strategy under review and look again at progress at its October meeting;
- note that:
 - the number of referrals to Dementia Advisors from GP surgeries was now 33 people (not 14 or 15 as listed in the report);
 - it would receive a report on the Carers' Support Project in due course.

Councillor Dr Peter Skolar undertook to:

- draw the attention of the Oxfordshire Joint Health Overview and Scrutiny Committee to the issue of Dementia; and
- suggest that it advises the Medical Committee and NHS Oxfordshire to look at the need to communicate to GPs about the ongoing importance of correctly diagnosing dementia - given that some GPs may be of the view that there is not much that they can do to assist following a diagnosis and that there are not many services in place - and to highlight the importance of early diagnosis both in terms of Health and Social Care for both the patient and their carer and family.