

**MINUTES OF A MEETING OF THE DEMENTIA TASK AND FINISH GROUP HELD AT COUNTY HALL, CHELMSFORD, ON 25 NOVEMBER 2010, COMMENCING AT 2 PM**

Membership comprises Members of the Health Overview and Scrutiny Committee (HOSC), the Community Wellbeing and Older Persons Policy and Scrutiny Committee, and a representative from each of the North Essex Mental Health Trust and South Essex Mental Health Trust

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|---------------------------|--------------------|
| * J Baugh (Chairman)      | Mrs M Hutchon      |
| * R Cox                   | * M Maddocks       |
| * S Currell (from 2.20pm) | * Mrs J Whitehouse |
| * Mrs S Hillier           |                    |
|                           | * Present          |

Also in attendance: County Councillor J Knapman (until 2.55pm) and Kay Ellis, from Essex and Southend Local Involvement Network (LINK) (who left the meeting at the conclusion of Item 3).

Officers in attendance were:

- Graham Redgwell - Governance Officer  
Graham Hughes - Committee Officer

**1. Apologies and Substitution Notices**

Apologies: County Councillor Mrs M Hutchon.

**2. Declarations of Interest**

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|---------------------------|---|
| Councillor John Baugh     | Spouse works in the National Health Service   |
|                           | Director Friends of Community Hospital Trust  |
| Councillor Sandra Hillier | Personal interest as governor of Basildon and |
|                           | Thurrock University Hospital Trust            |

**3. Witness session**

The Group received a report (DEM/24/10) from Kay Ellis, LINK, comprising a statement of views and concerns raised by carers. Kay Ellis was present at the meeting. Kay Ellis also was a volunteer member of the Alzheimers Society (AS) Branch at Epping and much of the discussion at the meeting was anecdotal evidence in relation to this Branch operation:

Carers and respite day care

- Respite care was valuable for carers but did it benefit the dementia patient as it could add to the confusion? The key was that any respite care should

offer stimulation for the patient, particularly whilst the patient was in the milder phase of the illness;

- If respite support was not provided, carers would give up earlier with earlier referral to formal care and the overall costs of formal care would significantly increase. Whole basis is to sustain them in the community with their families and maximise their time at home;
- 26 people received respite day care at the AS Epping Branch but there was an unmet demand (over 100 initial contacts and a varying waiting list which was currently 50). There would always be potential clients who did not register with them as their families thought that they could cope unassisted. The current level of funding was preventing further expansion;
- Better quality and dedicated day care facilities would lead to better treatment;
- Eligibility for parking permits for dementia patients was no different to anyone else and physical incapacity and disability remained the determining factor

#### Funding issues

- Received funding from ECC and Epping Forest District Council which covered the cost of day care (staff, building costs).
- Details of funding received by AS from district councils would be distributed to the members of the Group.
- Fixed term grant funding gave no long term security of funding to AS. ECC was moving towards longer grant award periods but it would still only be a maximum of three years.
- Suggested that there could be uncertainty of consistent funding for the AS Epping Branch operations if personal budgets were utilised by the majority of their clients. It was thought that they would only be paid on the day of attendance when clients arrived and they would not receive any monies for non-attendees.
- Meals on Wheels service for the AS Epping Branch had been re-sourced as the original distribution centre had been relocated to Basildon; they had wanted to know demand for meals before it was known how many clients were attending on the day. Now changed to a more flexible supplier based in Harlow.

- Some day care rates were extortionate (could be £60 a day). If the number of affordable dementia care facilities did not increase people would continue to struggle at home and the burden of care would increasingly fall on the family to cope for as long as possible. Thereafter, often the referral was straight to acute hospitals which was not always appropriate.
- Acknowledged that seemed to be a clear national and regional policy switch away from funding care homes to increasingly support dementia carers at home.
- Large proportion of dementia costs were on hospital beds, care homes etc and if the length of stay in these was reduced, by maximising the period sustained at home, it could facilitate funding being transferred away from such formalised care towards sustaining people at home for longer.
- Discussed if care was not fully funded (i.e. making a contribution) and the policy on surcharging property and charging orders.

#### Ideal Facilities

- AS wished for a purpose built building solely dedicated to dementia care. Currently they only used hired halls which was not ideal. An example was cited of artwork produced by dementia sufferers which was displayed on the walls during meetings which had to be removed at the end of every meeting rather than being able to leave it displayed.
- The AS would have liked adequate and dedicated car parking with good transport links. The problem with the current meeting facility for Epping AS was that they only had part use and part share of the car park.

#### Liaison

- There was existing liaison between AS and mental health trusts, PCTs and GPs but further co-operation was desirable. Current liaison was felt to be below a level that was appropriate and necessary.

#### Information

- Whilst there had been leaflet drops at GP surgeries, many of them did not display the literature. Leaflets had not been seen at Braintree Community Hospital either.
- Suggested that information leaflets etc should be made available to the patient and family at the time of the referral to a memory clinic so that potential patients and carers could be thinking about the issues arising during the typical seven week period leading up to the actual appointment.

- No advocacy/legal service was provided by AS. The Chairman of the Chelmsford Branch had previously raised this with the Chairman of the Group as being needed

### Care Homes

- Average length of stay for dementia patient in a care home was 18-24 months. It was arguable if life longevity was affected by the trauma of entry to care homes as entry was often at end-of-life- phase in any case. However there was a counter argument that removal of autonomy for a patient shortened lifespan.
- Reduction in prescription of anti-psychotic drugs.
- A proportionate number of staff at a private care provider should be trained to care for the number of beds registered for dementia care at that home
- The AS had a member of staff (a trained trainer) who visited care homes to train their care staff in dementia care. However, care homes generally had a high turnover of junior nursing and care staff and so the process was continual.
- Staff at care homes should be encouraged to get additional training and qualifications. However, there seemed to be a problem with a shortage of nursing care staff. Furthermore, there could be communication issues with staff for whom English was not a first language.
- There was a discussion on the desire for specialised dementia care homes. People suffering from dementia were not necessarily elderly and still needed cognitive and mental stimulation. This often would depend on the number of staff trained in dementia care on site; a dedicated dementia care home could mean more staff trained in dementia care on site.
- West Essex PCT stated policy was for development of smaller dementia care units within care homes rather than dedicated care homes solely for dementia care.
- It was suggested that, in future, local authorities may need to consider classifying dementia care facilities as a special case for planning application purposes, just like affordable housing.
- NIAS were running a Lifelong Learning Project whereby volunteers would go into care homes to undertake learning activities with residents. They were looking for nine volunteer local authorities to participate in the pilot scheme and an invite to participate had been sent to the relevant Cabinet Member at ECC.

### Mental Health Trusts

- Awaiting publication of Coalition Government Financial Operating Framework in December but it looked to be a challenging future financial environment for both mental health and acute hospital trusts.
- SEPT clinical criteria for accepting dementia cases was now more challenging. Steve Currell to provide further details.
- Needed good liaison with care homes. Memory services provided support to, and had links with, both the private and publicly funded care home sectors.
- It was generally recognised that there had to be an increase in dementia care capacity and that a clear overview strategy was needed with the voluntary sector (particularly the AS) seen as crucial to that strategy.

### GPs

- GPs could be the ones to see first signs of dementia. Some GPs were better at recognising early signs of dementia than others.
- Stronger liaison with GPs was needed as part of the establishment of GP commissioning so as to maximise outcomes.
- GP referrals in future would have direct financial consequences on the GP Consortia to which they belong.
- Suggested that should target Lead Players in future GP consortia. Current Lead names to be provided by Ray Cox/Steve Currell/Kay Ellis.

Kay Ellis was thanked for attending and then left the meeting.

## **4. Minutes**

The minutes of the meeting of the Group held on 13 September 2010 were approved as a true record.

## **5. Matters Arising from last meeting**

Further papers and information was received as listed below with any resulting discussion minuted under each item:

- (a) Information on the Thinking Fit Programme (DEM/12/10) was received:

- People with mild cognitive impairment (MCI) were at increased risk of developing dementia with approximately 8 out of 10 people with MCI developing dementia within 6 years after initial diagnosis.
- ECC and NEPFT were running a new research programme of multiple activities to stimulate physical, intellectual and social activity amongst individuals referred to a memory clinic and diagnosed with MCI, to determine if the further onset of dementia could be delayed. Also involved Adult Community Learning and Essex Libraries. The work was funded by a grant from Essex Adult Social Care. The activities were designed to be low cost and capable of being carried out in a group or individual setting. The project was operating in the west of the county at present with potential to expand into other geographical areas.
- (b) Further information on the Alzheimer's Society Public Information Officer (DEM/13/10) was received; It was funded through a one-off ECC Community & Voluntary Services Grant . Information had been provided by the post holder to over 8000 people in the period April-October 2010 in a variety of public and private venues.
- (c) Further information on ECC funding for voluntary organisations which specialise in supporting people with dementia and their carers (DEM/14/10) was received. Members questioned whether any of the funding was protected and noted that it was likely to be only for one year although there was general trend towards 3 year awards.
- (d) Further ECC information on services provided by the Alzheimer's Society in Epping Forest District (DEM/15/10) was received;
- The Dementia Support Service provided one to one information, guidance and support to people living with dementia and their carers; 199 recipients of this service in first four months of financial year (113 of them carers).
- Dementia Support Workers received training for their role from the Alzheimer's Society; and liaised with relevant statutory and voluntary organisations on behalf of service users;
- Twice weekly Day Care Service (received grant funding from ECC) accessed by 26 people providing breaks for 29 carers.
- Befriending/Leisure and Wellbeing Service – received ECC funding for one to one support to people with dementia to enable them to maintain, regain or develop skills, social networks and leisure interests;

- Dementia Care Advisors – West Essex PCT and ECC supported three ‘outreach’ post holders to support people through the period surrounding diagnosis.
  - Supported younger people with dementia and their carers – a monthly support group had been established.
  - There was an inconsistent level of service offered by the Alzheimer’s Society across different districts;
- (e) Response received from regional office of the Alzheimer’s Society (DEM/25/10) which outlined the following issues:
- (i) delays and discrepancies in receiving a diagnosis;
  - (ii) carers and people with dementia struggled to obtain good quality and prompt information with carers finding it difficult to navigate around the benefits and care systems;
  - (iii) AS encouraged the use of personalised budgets but suggested that social workers were not consistently providing this option;
  - (iv) inconsistent respite care available with carers often just wanting cover for a few hours for shopping, hair appointment etc ; issues about planning for ‘time-off’;
  - (v) there were some voluntary groups who provided a ‘sitting service’;
  - (vi) places for day care services were limited in some areas;
  - (vii) lack of training and understanding of dementia by ambulance and acute sector staff;
  - (viii) carers experienced distress when making a decision to ‘let go’ of the caring role with little subsequent support for them;
  - (ix) concerns regarding levels of care and ability of care home staff. AS were supporting care homes and had commenced a project with SW Essex PCT to look at staff training in 10 care homes.
- (f) The Governance Officer was instructed to send a follow-up request to the Local Medical Committee inviting them to submit copies of the advice provided to GPs in respect of dementia care (DEM/16/10).
- (g) ECC Connecting Carers (Winter 2010) brochure was received (DEM/19/10); Members to be advised who actually received the mailing of the document.

## 6. Further information

- (a) Department of Health – Quality outcomes for people with dementia: building on the work of the National Dementia Strategy (September 2010) (DEM/20/10) was received and noted;
- Members highlighted the apparent omission of reference to the role of GPs which would prevent a comprehensive joined-up approach;
- Copy of National Dementia Declaration to be circulated to Members.
- (b) National Institute for Health and Clinical Excellence (NICE) – Alzheimer's disease: appraisal consultation document (DEM/21/10) was received and noted .
- (c) Alzheimer's Society – Living with Dementia magazine (November 2010) and archive contents listing for previous editions of the magazine published in 2010 (DEM/22/10) was received and noted;
- (d) Received list of Living with Dementia booklets available from the Alzheimer's Society and two samples (DEM/23/10) and these were received and noted
- (e) Reference was made to a company providing 'Dementia Adventure' – volunteers took patients on a walk and talk in one of three Essex country parks.

## 7. Further Evidence/Draft Final Recommendations

Members suggested academic evidence was needed on cost effective approaches and likely best route for allocating resources. Suggested contact Martin Cleverley, Clinical Research Fellow, at NEPFT.

Further information to be sought on:

- (i) the proportion of patients in care with dementia that were actually funded by ECC;
- (ii) Demand for care beds that were privately and ECC funded; information was only likely from MH Trust so may need to contact both MH Trusts to get whole picture.

Members discussed likely early Findings of Group but agreed that further evidence (as above) was required to finalise such Findings.

## 8. Scoping Document



The Group agreed that the current Scoping Document remained an accurate reflection of the Group's focus and work to date.

**9. Urgent business and exclusion of the public**

It was AGREED that the public (including the press) should be excluded from the remainder of the meeting during consideration of an agenda item on the grounds that it involved the likely disclosure of exempt information as specified in Part I of Schedule 12A of the Local Government Act 1972.

**10. Provision and funding of dementia beds**

- The Group received further information on the various assumptions used in connection with calculating the numbers of people with dementia financially supported by ECC.

The meeting closed at 4 pm.

Chairman