MINUTES OF A MEETING OF THE DEMENTIA TASK AND FINISH GROUP HELD AT COUNTY HALL, CHELMSFORD, ON 9 MARCH 2011, COMMENCING AT 2.15 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

*	J Baugh (Chairman)		Mrs M Hutchon
*	R Cox		M Maddocks
	S Currell	*	Mrs J Whitehouse
*	Mrs S Hillier		

* Present

Also in attendance: Martin Cleverley, Clinical Research Fellow, and Dr Thomas Dannhauser, (for items 1-3 only) and Mark Curteis, Heritage Learning and Access, Essex Record Office (items 1-4 only)

Officers in attendance were:

Graham Redgwell	-	Governance Officer
Graham Hughes	-	Committee Officer

1. Apologies and Substitution Notices

Apologies: County Councillor Mrs M Hutchon, S Currell and District Councillor M Maddocks.

2. Declarations of Interest

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 Thinking Fit Programme

- Martin Cleverley, Clinical Research Fellow, and Dr Thomas Dannhauser, from the North Essex Partnership NHS Foundation Trust (NEPFT) joined the meeting;

- Received reports (DEM/01/11, DEM15/11, DEM/16/11 and DEM 17/11) with details listed in Appendix 1;

(a) Background

- It was estimated that there were 1.7 million people in the UK with Mild Cognitive Impairment (MCI) and/or dementia;

- UK Annual Societal Cost of dementia (£23 billion), cancer (£12 billion), heart disease (£8 billion) and stroke (£5 billion), with a disproportionate amount of research spent on each of £0.05b, £0.59 b, £0.17 b, and £0.2 b respectively;

- 95% of the cost of dementia was in social care (and informal care) whereas there was much higher proportion of formalised health care contributing to costs for treatment of cancer, heart disease and stroke;

- No cure for dementia on the horizon;

- Some hope for prevention or delay. If delayed sufficiently, people could die from other causes that have lower morbidity and higher mortality.

(b) Research

- Research showed that certain activities had beneficial effects and could significantly reduce dementia risk: regular exercise by up to 49%, social interaction activity by up to 51% and use of computer by up to 51% and by up to 63% when all three activity groups were combined;

- 90% risk of decline for those with MCI to dementia within six years;

(c) Development of the Thinking Fit programme

- In partnership with Adult Community Learning Teams the Thinking Fit Project had developed a package of programmes and activities which could be dedicated centre-based or home based;

- In the case of home based participants, internet and teleconferencing access was provided to facilitate social interaction and other computer activities;

- Looking to see if those people already showing signs of MCI could, through being engaged in various activities, maintain cognition and independence for longer;

- Patients already with more severe cognitive impairment would have to be engaged differently and would need additional support to participate. Those with severe dementia were not appropriate to participate.

- Looking to see if healthy activities could be made to be fun, locally available and could engage patients long-term;

- Four month development period was followed by first year, with the programme now due to run for another year

(d) Identifying the participants

- Target sample size for the overall pilot programme was for 128 participants. Pilots already completed in Epping and Harlow areas. Great Dunmow cluster planned to commence in April. The Crystal Centre planned for later in 2011 for a Chelmsford based cluster, and also looking at a Braintree and Maldon cluster.

- NEPFT sought groups of eight willing participants in each area prior to determining a convenient centre for the activities.

- MCI participants were more reluctant to engage in groups and tended to socially isolate, therefore ordinarily extra time would be needed to engage them so as to prevent them from self-excluding.

- Selection criteria was made as wide as possible to include a varied selection of secondary diagnosis;

(e) Details of the Thinking Fit programme

- Programme for participants was for six months;

- Established psychological techniques – a month before commencing the programme, the intended participants were given a particular activity (Do-Something-Different-Everyday, Prof B.C. Fletcher, Prof K.P. Pine, University of Hertfordshire) as preparation for the programme which purposely would disrupt their usual routine. Changing lifestyle behaviours to reverse the effect of a sedentary lifestyle was promoted by first upsetting the current living pattern;

- This was followed by the gradual introduction of the activity programme, first accompanied walks (or other physical activity) for two weeks, then meeting the centre-based staff and starting other activities including computer work. Each participant was expected to participate in three walks (or other physical exercise), one social activity and one brain training activity each week;

- Participants were required to participate in at least 50% of activities

- Heart rate monitors with audible and vibration alerts were provided to encourage physical activity (not exclusively walking – could be cycling or

other activity) three times a week, at 75%-65% moderate heart rate intensity, for 30 minute duration each time so as to improve cardiovascular fitness and significantly increase oxygen to the brain;

- Social activity programmes were kept secret so that participants did not know what they would be doing in advance. Such 'new learning' provided greater stimulation and engagement in tasks that they had not done before and might not have otherwise been keen to try. Examples of these 'new' activities were using digital cameras and learning sign language;

- Information was given to participants in small 'bite-sized' bits, more than once and in more than one communication form.

- Brain training/brain fitness programme (Lumosity), to be undertaken for 90 minutes a week, was divided into various computer based thinking exercises that included word finding and problem solving, which could be done at home or in a library;

- Safeguards were in place for computer use by the participants; for example, these could be set up to a portal that only allowed access to certain sites to prevent exploitation by third parties.

- Programme was designed in such a way so as to make people engage in a way that they would enjoy.

(f) <u>Costs, value for money</u>

- Average cost of caring for someone with dementia in the UK was £27,000 per annum. Made clear sense to invest to keep people active rather than pay for care;

- Estimated £4,000 cost per person for developing the Thinking Fit Programme but expected that, over time, the ongoing cost of running an established programme would be significantly less;

- 128 people would accrue approximately 375 years of dementia care;

- Payback period calculated - only have to show 4.5% per head effect on reducing the demand for dementia services for it to pay back. Already known that 50% of MCI decline to dementia was over six years from first symptoms, one could measure the long term effects of an extended programme against that statistic;

- Key to the Programme's success was to obtain funding to continue beyond the pilot period and set up a sustainable structure offering value for money;

- 'Can't afford not to';

- Improved quality of life;

- It was hoped that there would be some element of goodwill established with partner organisations to continue at least some activities beyond the end of the term of the Programme;

- Already identified that there were also significant benefits to partners and carers in having respite cover whilst the individuals were undertaking some of the activities;

(g) The future

- Use of volunteers in future to run some or all of the programme? Would need to produce same consistency and standard and be capable of delivering the whole model and not just selective and preferred parts of it: Libraries were possible future partners as they had some relevant experience;

- Members highlighted the University of the Third Age and discussed how to get the best use of existing resources in the County;

- A Thinking Fit Plus Scheme (with a participatory group following through with ongoing activities) was being trialled at Epping Library, and could set up a precedent for future follow-up work;

- Martin Cleverley and Dr Thomas Dannhauser were thanked for their evidence and they then left the meeting.

4. Witness session – The Essex Reminiscence Network Project and the development of memory boxes

- Mark Curteis, Heritage Learning and Access, Essex Record Office, gave evidence;

- Received various reports (DEM/02/11) with details listed in Appendix 1;

(a) Background

- The Essex Reminiscence Network (ERN) aimed to provide reminiscence sessions and support for older people in care settings;

- Support provided directly, and also indirectly through training carers and others wishing to undertake reminiscence work;

- Reminiscence therapy had been shown to improve well being and communication, identity, integration, self worth and understanding between patient and carer;

- Could be used as an intergenerational tool, and/or establish common memories and also ones that were different but which different people could relate to. This could assist relationships between patients and/or with carers;

- Could help the carer in personalising future carer support by learning about the background and knowledge of the patient and the issues that matter to them. Helps write a life story. May help to explain unusual behaviour.

(b) Reminiscence therapy sessions

- The Memory Box used old household and personal objects to trigger memories (smell was an important trigger);

- The participant chose what to say in response to memories jogged and the session was not judgmental. The sessions would still work even if the participant was unable to speak, as long as they could point or indicate answers and comments;

- Reminiscence sessions were usually 1 to 1 or in small groups.

- Reminiscence therapy could be targeted at both those with MCI and those with dementia;

- Could be a one-off exercise or a series of visits;

- Sessions could be organised specifically for those born and/or raised outside the UK (being trialled in Maldon).

(c) Training carers

- More focussed on training carers so that they can lead the session as this particular care model was more sustainable in the future;

- Important that training was delivered in such a way so as to maintain ongoing quality of the reminiscence therapy;

- The training supported carers and gave them skills for developing their own personalised reminiscence programme;

- Part of the training was to avoid revisiting upsetting memories;

- ERO had trained over 500 carers in past 6-7 years. Most recently worked with Essex Cares and they had established Champions in their Day Centres;

- Two staff were involved in this work. It took up about 60% of Dr Curteis' time.

(d) Funding and the future

- Reminiscence therapy was seen to be beneficial. ERO had secured ECC and external funding and would be looking to develop Heritage Lottery bids;

- Ray Cox would investigate if North Essex Foundation Partnership Trust could offer any support as it seemed to be an integral part of carer training;

- There were capacity constraints and charging for the reminiscence therapy service was potentially an untapped revenue source in future;

- Planning for ERO to have larger number of memory boxes to hire out as well as encouraging people to put together their own boxes;

(e) Publicity

- Public sessions (such as in the libraries and museums) were typically advertised through the Alzheimer's Society (AS);

- Arguably this publicity route was only tending to reach out to those already engaged (through involvement in the AS);

- Need to find a way to reach those not already engaged (isolated);

- Carers would attend on their own (without the patient) although the AS also did do a reminiscence therapy session with both carers and patients;

- Essex Reminiscence Network was seen as good practice and had been copied by Cambridgeshire, Hertfordshire and Suffolk County Councils. Essex had taken the lead role in regional activity.

- Mark Curteis was thanked for his evidence and he then left the meeting.

5. Minutes

The minutes of the meeting of the Group held on 25 November 2010 were approved as a true record subject to NIACE replacing NIAS on the last bullet point under Minute 3 – Care Homes on page 23.

6. Matters Arising from last meeting

Further papers and information were received (as listed in Appendix 1) and briefly discussed:

- Members still concerned about GP engagement with dementia issues and whether it specifically was included in continuing professional training;

- Discussion on the possibility of memory clinics being located in GP surgeries and whether there could be more partnership working;

7. Further Evidence/Draft Final Recommendations

- Members **Agreed** that no further witnesses were required;

- Draft template Scrutiny report had been circulated and was briefly discussed. An updated report to be circulated by the Governance Officerfor discussion at the next meeting;

- Private 'workshop' session to be arranged to finalise findings and recommendations to go to the Essex HOSC meeting in June 2011 [Committee Officer note: subsequently arranged for Tuesday 5 April].

8. Scoping Document

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

The meeting closed at 4.30 pm.

Chairman

APPENDIX 1

Copies of reference documents received by the meeting:

- Protocol for the Thinking Fit project (University College London and North Essex Partnership Foundation NHS Trust)
- Essex Reminiscence Network (ERO)
- Recollection and the UK Museum: Object, Image and Word (University of Leicester)
- The effects of reminiscence on depressive symptoms and mood status of older institutionalised adults in Taiwan (Fooyin University)
- Reminiscence therapy with older adults (E O'Leary and N Barry)
- Effect of reminiscence therapy on depression in older adults: a systematic review (Fooyin University)
- The effect of reminiscence on the elderly population: a systematic review (Fooyin University)
- Reminiscence therapy for dementia (The Cochrane Collaboration)
- Disabled Parking Badge scheme for parking concessions for disabled and blind people (ECC)
- Alzheimers Society funding (Alzheimers Society)
- Views on dementia services (Epping Forest PBC Consortium)
- Views on dementia services (Ranworth Surgery, Clacton-on-Sea)
- Dementia Action Alliance and National Dementia Declaration for England (DAA)
- Case studies (Alzheimers Society and ECC)
- Support, Stay, Save (Alzheimers Society)
- Services provided by Alzheimers Society in West Essex (Alzheimers Society)
- Dementia 2010: the economic burden of dementia and associated research funding in the United Kingdom (Alzheimers Research Trust)
- World Alzheimer Report 2010: the global economic impact of dementia (Alzheimers Disease International)
- Preventing Alzheimers disease and cognitive decline (US Department of Health and Human Sciences)
- Advice to General Practices (Essex Local Medical Committee)
- Thinking Fit progress report (North Essex Partnership NHS Foundation Trust)
- Lesson Plan: reminiscing with older people (ERO)