

By: Sue Frampton, Policy Overview Research Officer

To: Dementia Select Committee, Adult Social Services Policy  
Overview and Scrutiny Committee  
5 January 2010

Subject: Topic Review – Services and support for people with dementia  
and their carers in Kent

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Summary: To discuss the Terms of Reference and general approach of the Dementia topic review.

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## 1. Introduction

- 1.1 The Department of Health estimates that there are more than 750,000 people in the UK with dementia and numbers could reach almost 1.5 million in the next 30 years. Though it more frequently affects older people, around 15,000 people in the UK have early-onset dementia (i.e. before age 65). There are hundreds of variations; the dementias affecting the greatest numbers of people being Alzheimer's disease, vascular dementia, fronto-temporal dementia (Pick's disease) and dementia with Lewy bodies. There are also mixed dementias.
- 1.2 *'The term 'dementia' is used to describe a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness.'*  
National Dementia Strategy, 2009
- 1.3 Dementia profoundly affects people's lives and the lives of those who care for them, this caring role frequently being taken on by family and friends.
- 1.4 It is vital that the Select Committee carrying out this review is focused and maintains its impetus throughout the work. It is equally vital that the views of people with dementia and those of carers are kept central throughout and therefore the scope proposed at this stage will be refined by discussion between the members of the Select Committee and a focus group, drawn together for the purpose. Select Committee Membership is as follows:

Mrs Trudy Dean	(Liberal Democrat) Chairman designate
Mrs Ann Allen	(Conservative)
Mr David Brazier	(Conservative)
Mr Alan Chell	(Conservative)
Mr Nigel Collor	(Conservative)
Mr Steve Manion	(Conservative)

Mr Ken Pugh (Conservative)

Mr Avtar Sandu (Conservative)

Mr Leslie Christie (Labour – co-opted Member)

## **2. Terms of Reference – for discussion**

2.1 TOR for this work could cover one or more of the following:

- a) Explore the current and predicted prevalence of different types of dementia in Kent and the implications for future services.
- b) Investigate modifiable risk factors for dementia and identify actions that could be taken by KCC, NHS and others including individual residents to contribute to a reduction in the prevalence of dementia in Kent in the future.
- c) Explore opportunities for more integrated, person centred care and support for people with dementia, highlighting innovation and best practice and focusing on issues of dignity and equality.
- d) Consider how to provide better support for carers of people with dementia.

2.2 Alternatively, Members may wish to take the review forward under more general terms of reference such as:

"To identify opportunities for the provision of community-based services which are better tailored to the needs of people with dementia and their carers, focusing on issues of dignity, respect and quality of life."

## **3. Scope/Themes – for discussion**

3.1 This review will need to consider various cross-cutting themes. The wish to involve stakeholders from the outset will require flexibility during the early stages so that, for example, focus group members can have direct input to the scope of the review and the views of people/organisations who write in can be taken into account. A range of issues that could potentially be covered are noted below.

### *Prevalence & Prevention*

- What is currently known about health/lifestyle choices such as healthy eating, drinking alcohol and mental/physical activity as risk/protective factors for dementia and what is known about their potential for decreasing the prevalence of certain types of dementia?
- How could public health messages on dementia be communicated effectively?

### *Innovations and best practice*

- How can the quality of life for people with dementia be improved at different stages of their illness (greater understanding about dementia including among professionals; how and where dementia is diagnosed; activities; life-story work)?

- What is the role of technology in helping people with dementia and what are the ethical issues?
- What factors could contribute to a more dementia-friendly community?

#### *Carers' support*

- Did the KCC Carers Review in 2006 and subsequent Kent surveys highlight issues particularly relevant to caring for people with dementia?
- How can carers be better included and supported on issues such as managing finances, making healthcare decisions and at times of transition (such as pre- and post- diagnosis, when a person with dementia has a period in hospital, or requires more specialised care, at times of crisis); how can the relationship between person with dementia and their carer/s be supported?. Where are the gaps?
- Is the information available for people with dementia and their carers accessible and in appropriate formats?

#### *Equalities Issues*

- What is known about the perception of dementia within different communities in Kent and how this impacts on both people with dementia and their carers.
- How could stigma associated with dementia be reduced?
- What are the factors that prevent people from seeking diagnosis?
- What additional challenges are there in relation to diagnosis and dementia care for people with sensory difficulties or learning disabilities

## **4. General Approach – for information**

4.1 A multi-faceted approach to this review is proposed. The first phase involves research; publicising the review to individuals, groups and voluntary sector contacts informal discussions with stakeholders and the formation of a focus group; phase 2 involves a series of visits to organisations/establishments involved with dementia care and/or support; phase 3 involves formal Select Committee Hearings. It is envisaged that some of these may take the form of 'panel discussions'. (The timescale for the review has been extended, which will facilitate the additional time required to meet with the focus group and to respond to the questions and issues raised by stakeholders invited to participate. The extended timescale also provides the opportunity to hold further meetings if required.

### Phase One – December 2010/January 2011

- Desk-based research
- Establish reading list for Members of the Select Committee.
- Introductory briefing
- Set up Select Committee 'informal' training session to raise awareness of dementia issues and prepare for visits
- Arrange for briefing by Adult Social Services/Health
- Invite stakeholders to express their interest in/wish to participate in the Select Committee in writing.
- Set up a focus group as a point of reference throughout the review; arrange first meeting

- Set up visits for February
- Set up Select Committee Hearings for March.
- Identify questions/themes to be posed to witnesses
- Request written information required in advance of meetings
- Liaising with Tunbridge Wells Borough Council who are undertaking a locally focussed review of dementia.

#### Phase Two – March/April 2011

- Meetings of Select Committee with key people, organisations or groups to gain understanding and insight into the issues facing people with dementia and their carers, the services available and the options for the future.
- Identifying additional evidence required and applying for further written information
- Production, agreement and publication of minutes

#### Phase Three – May/July 2011

- Reading evidence
- Meeting of Select Committee with focus group to discuss evidence and recommendations
- Report writing

#### Phase four – formal sign off processes August/December 2011

### **5 Briefing and training – for discussion**

#### 5.1 Informal Briefing & Training

It is proposed that an informal briefing and training session is held at the beginning of the review to gain an understanding of the topic and of current and planned dementia services. A briefing paper may be provided in support.

#### 5.2 Visits

Members have been requested to set aside 6 days/half days for visits (in order that we can offer some flexibility to venues when arranging). Dates reserved are:

Weds 2 <sup>nd</sup> Feb	pm
Friday 4 <sup>th</sup> Feb	pm (set aside for Conference attendance)
Monday 7 <sup>th</sup> Feb	all day
Friday 11 <sup>th</sup> Feb	am
Weds 23 Feb	all day
Mon 28 Feb	all day

It is proposed that:

- *visits are carried out by one or two Members (supported by an officer, where possible) and that Members report back to the committee*
- *one of these dates is used for a meeting with the focus group*

Venues could include:

Age Concern dementia day care facility, Bearsted  
 Alzheimer's Society Park Lodge Day Services, Tudley  
 Alzheimer' and Dementia Support Services Day Centre, Gravesham  
 Bupa Nursing Home (Priory Mews), Dartford  
 KMPT in patient unit  
 One or more Memory Cafés (there are 5 in Kent)  
 A peer support group  
 Hazel Neville (Dementia Care) Centre, Herne Bay  
 Westbrook House Integrated Care Centre, Margate  
 CARM (Caring Altogether in Romney Marsh) – 'Our Memories Matter' session

### 5.3 Hearings/Witnesses

It is proposed that initially 6 half or full days are set aside for Select Committee hearings in March/early April. (Sessions will usually be half days within these slots).

Weds 9 <sup>th</sup> March	all day
Weds 16 <sup>th</sup> March	all day
Weds 23 <sup>rd</sup> March	all day
Tues 29 <sup>th</sup> March	pm
Tues 5 <sup>th</sup> April	all day
Friday 8 <sup>th</sup> April	all day

Meetings will be open to the public unless there is a particular requirement for a closed session. Suggested witnesses/organisations who could be invited to attend are shown below (this list is a starting point and changes may be needed dependent upon the scope as it develops). *Please note that people with dementia will be engaged through the focus group and via carer/other organisations. Topics are cross-cutting and given for guidance/planning purposes only. Some witnesses may instead/in addition be participating in the focus group or may prefer to submit written evidence.*

DH Perspective	Ian Bainbridge – Deputy Regional Director of Social Care, Dept of Health South East (Transforming Adult Social Care Programme Board)
KCC Provision	Jane Barnes – Head of Provision – Modernisation (Older People), Adult Social Services
Commissioning (Health/Social Care)	Emma Hanson - Joint Commissioning Manager Dementia West Kent Adult Social Services & West Kent NHS Mike Powe – Head of Service, Canterbury and Swale Linda Caldwell – Lead Commissioner for Older People's Services, NHS Eastern and Coastal Kent
Prevention/Public Health	Meredin Peachey, Kent Director of Public Health
Health – General Practice/Mental Health	Dr GMH Kanagasooriam, (Named Clinical Lead for Dementia in East Kent) Dr James Kelly, Local Medical Committee Erville Miller, Chief Executive, KMPT

	Fiona Martin, Admiral Nurse Clinical Lead
Best Practice, Innovations and Activities	Nada Savitch, Director, Innovations in Dementia Community Interest Company Sidney De Haan Research Centre for Arts and Health NAPA (National Association for Providers of Activities for Older People) Personal Social Services Research Unit (PSSRU) University of Kent Dr Catherine Henderson, London School of Economics U3A (University of the Third Age)
Carers & Carers' Support	Naomi Hill – Adult Social Services Policy Officer – Carers Barbara Hagan – Director, Maidstone Carers Project Crossroads Care Volcare Megan Jones, Alzheimer's Society Individual carers
Domiciliary & Residential Care & Support	Jacqui Morris, Director of Practice Development, Avante Care and Support
Dignity in Care	Joanna French, Quality Assurance and Practice Development, West Kent Adult Social Services
Community Resilience	Uta Critchley, Emergency Planning Officer Kent Search & Rescue Kent Police Kent Fire & Rescue

#### 5.4 *Written views/comments*

It is proposed that the following people/organisations are invited to share their views, highlight issues or provide written answers to specific questions:

- Voluntary Sector Support organisations
- Distribution list of approximately 30 individual carers
- Witnesses invited to but unable to attend hearings
- Witnesses attending hearings (prior to or after hearings as appropriate)
- GP Practices via questionnaire
- Members of the public via press release (it is suggested that this method is employed to elicit responses to specific questions once the review is under way)
- Other Local Authorities who have undertaken reviews on the topic (as well as international examples of best practice)

#### 5.5 *Other Select Committee Meetings*

It is suggested that the Select Committee meets with a focus group to discuss the scope of the review and later its findings and recommendations. The Select Committee will also meet to comment on the draft report and seek comment from the directorate and Cabinet Member.

## 6. Proposed Timetable (summary)

26<sup>th</sup> January Informal briefing/training session

February **Visits/conference** (provisional dates listed below)

Weds 2 <sup>nd</sup> Feb	pm
Friday 4 <sup>th</sup> Feb	pm
Monday 7 <sup>th</sup> Feb	all day
Friday 11 <sup>th</sup> Feb	am
Weds 23 Feb	all day
Mon 28 Feb	all day

March/April **Hearings** (provisional dates listed below)

Weds 9th March	all day
Weds 16th March	all day
Weds 23rd March	all day
Tues 29th March	pm
Tues 5th April	all day
Friday 8th April	all day

May/July **Evidence/Recommendations/Report Writing**

August/Dec **Formal processes**

- Select Committee finalise/agree report
- Select Committee share report with Cabinet Member and ASS Directorate
- Select Committee share report with Corporate Management Team
- Report considered by ASSPOC
- Report published to Cabinet
- Report considered by Cabinet
- Report considered by County Council

## 7. Project Risks/responses:

- 7.1 The review takes place at a time of major reorganisation of Health Services and of Kent County Council Directorates. Processes will be transparent in order to facilitate continuity.
- 7.2 The months of April and May have been largely deselected for meetings. (Timescales for reporting have been extended from the originally proposed July County Council meeting to December's meeting.)
- 7.3 The Select Committee wish to invite wide involvement in the project. The Directorate has been helpful in acting as liaison with contacts to whom the letter of invitation to participate will be circulated. In addition Alzheimer's Society and Maidstone Carers' Support have offered assistance.

**Recommendation:**

To agree the Terms of Reference and general approach to the review of dementia.

**Review contacts:**

Policy Overview Research Officer -  
Sue Frampton  
Tel No: 01622 694993  
email: sue.frampton@kent.gov.uk

Democratic Services Officer  
Christine Singh  
Tel No: 01622 694334  
email: christine.singh@kent.gov.uk