

By: Mr Graham Gibbens, Cabinet Member for Adult Social Care and Public Health
Anne Tidmarsh, Director of Older People and Physical Disability

To: Cabinet – 5th December 2011

Subject: Select Committee: Dementia – a new stage in life

Summary: To receive and comment on the report of the Select Committee on Dementia

1. Introduction

The Adult Social Services (now the Adult Social Care and Public Health) Policy Overview and Scrutiny Committee proposed the establishment of a Select Committee to look at issues around services and support for people living with dementia in Kent. This was agreed by the Policy Overview Co-ordinating Committee (now the Scrutiny Board) at its meeting on 16 October 2009 following publication of a National Dementia Strategy in February of that year. On 28 September 2010 the Coalition Government published its own implementation plan for the Strategy: Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy. The Select committee was established shortly before Christmas 2010 and determined from the outset to keep as a central focus of the work, the views and concerns of people with dementia and their family carers.

2. Select Committee

2.1 Membership

The Chairman of the Select Committee was Mrs Trudy Dean, other members being Mrs Ann Allen, Mr David Brazier, Mr Alan Chell, Mr John Kirby, Mr Steve Manion, Mr Ken Pugh, Mr Avtar Sandu. In addition, Mr Leslie Christie was co-opted onto the Committee.

2.2 Terms of Reference

The Select Committee agreed draft Terms of Reference in December 2010 and determined that the scope would remain flexible until a number of key issues had been identified by people with dementia and carers taking part in the review. Final terms of reference were:

To examine issues around the '9 Steps' of 'Quality Outcomes' for people with dementia and their carers in Kent¹.

¹ Department of Health (2010)

The 9 Steps Draft synthesis of outcomes desired by people with dementia and their carers: By 2014, all people living with dementia in England should be able to say:

- I was diagnosed early
- I understand, so I make good decisions and provide for future decision making
- I get the treatment and support which are best for my dementia, and my life
- Those around me and looking after me are well supported
- I am treated with dignity and respect
- I know what I can do to help myself and who else can help me
- I can enjoy life
- I feel part of a community and I'm inspired to give something back
- I am confident my end of life wishes will be respected. I can expect a good death.

To identify good practice and innovation in Kent and elsewhere, that could contribute to achievement of the '9 steps'.

To identify factors militating against achievement of the '9 steps' and make recommendations for improvements.

2.3 *Evidence*

The Committee obtained information from a variety of sources to inform the review and began its work with an informal training and briefing session hosted by the Alzheimer's Society, followed by visits to a number of sites including care homes, peer support groups and memory cafes. Oral and written evidence was gathered from stakeholders including people with dementia and family carers. An invitation was extended to carer and client groups to comment and two consultation events were held for people living with dementia, carers and supporters; one in East Kent and one in West Kent, in collaboration with the Patient Advice and Liaison Service (PALS), KMPT East Kent. The views of people living with dementia and family carers remained central throughout the review process. A focus group comprising professionals involved in different aspects of dementia health and social care met twice during the review to inform the Terms of Reference and later to contribute to Members' discussion of recommendations. A list of the witnesses who attended Select Committee hearings is attached at Appendix 1 and a list of contributors who submitted written and supplementary evidence is attached at Appendix 2.

2.4 *Timescale*

Having begun its work with a training/briefing session in January 2011, the Select Committee conducted a programme of visits during February and formal hearings during March and April. Following a break in May, there was then a period of written evidence gathering and consultations. The Select Committee met with the Cabinet Member and Directors on 22 July 2011 to receive and discuss draft recommendations following which a report was

compiled during the summer. A draft report was sent for comment to a number of people living with dementia; carers and the professionals' focus group. The report was finalised after a further meeting of stakeholders in October. It will also be on the agenda of the Adult Social Care and Public Health POSC in November and considered by a meeting of Full Council on 15th December 2011.

3. The Report

3.1 The Select Committee report covers a number of aspects of this important topic and is supportive of work already under way in Kent to develop a dementia care pathway that will provide more seamless support to people living with dementia. This work will be supported by the Social Innovation Lab Kent (SILK) which will take forward recommendations, working with people with dementia and family carers.

3.2 Key themes of the report's 17 recommendations are:

- Improving and streamlining support for people with dementia and their carers within their communities
- Improving the rates of (early) diagnosis in Kent
- Extending the reach of the Admiral Nursing service
- Raising public awareness and understanding of dementia, including minimising the risk of developing vascular and other dementias
- Ensuring that children and young people know about dementia and encouraging intergenerational support
- Acknowledging and supporting the vital role of family carers
- More consistent and appropriate domiciliary and respite care
- Raising awareness about the Lasting Powers of Attorney (and possibly providing a service)
- Ensuring people have the information they need about dementia and dementia services
- Improving the level of dementia awareness and training for enablement workers and ensuring through contractual arrangement that homecare provider organisations can meet the needs of memory impaired clients
- Integrated working on dementia and pooling of budgets between health and social care
- Identifying current resources for dementia and modelling future spending
- Raising GPs' awareness of dementia
- Improving support for people with younger onset dementia
- Ensuring people with dementia and family carers are central to service development

3.3 An Executive Summary of the report is attached at Appendix 3. To obtain a copy of the full report, please contact the report author.

4. Conclusion

4.1 We welcome the report and would like to congratulate the Select Committee on completing this piece of work.

4.2 We would also like to thank all those witnesses, particularly people living with dementia and their carers, who gave evidence to the Select Committee and the officers who supported it.

4.3 Mrs Trudy Dean, Select Committee Chairman, will present the report to Cabinet and the Committee would welcome your comments.

5. Recommendations

5.1 The Select committee be thanked for its work and for producing a relevant and balanced document.

5.2 The witnesses and others who provided evidence and made valuable contributions to the Select Committee be thanked.

5.3 Cabinet's comments on the report and its recommendations be welcomed.

Background Information:

Department of Health (2010) Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy. [Online]. London: DH Available from:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119828.pdf [Accessed September 2011]

Select Committee Research Officer:

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Appendix One: Witnesses attending formal hearings:

9th March 2011

Panel Discussion: (Carers and former carers)

- Jack Gibbons
- Susan Long
- Geoff Grabham
- Doreen Cornelius
- Denise Lintern
- Judy Ayris, Dementia Outreach Service for Carers, Age UK Canterbury
- Barbara Hagan, Manager, Maidstone & Malling Carers Project

Panel Discussion: (Carers and former carers)

- Gill Bell
- Jeanne B
- Belinda Merritt
- Sally-Ann Clarke
- David Russell
- Jo Williamson

Interview:

- Ian Bainbridge - Deputy Director for Social Care & Local Partnerships, Department of Health South East (Deputy Regional Director of Transforming Adult Social Care Programme Board)

16th March 2011

Interview:

- Naomi Hill, Team Leader – Deafblind (current post)

Panel Discussion:

- Irene Jeffrey, Chief Executive, Crossroads West Kent
- Kate Gollop, Manager, Volcare
- Tanya Stephens, Carer Support worker, West Kent NHS Carers Support Project

Interview:

- Oliver Mills, Managing Director, Kent Adult Social Services (KCC)

23rd March 2011

Interviews:

- Pat Brown, Admiral Nurse Clinical Lead (East Kent) and Fiona Martin, Admiral Nurse Clinical Lead (West Kent)
- Edith Megbele, Community Mental Health Nurse
- Dr John Ribchester, Senior Partner, Whitstable Medical Practice

29th March 2011

Interviews:

- Michael O'Dell, Carer's Watch
- Simon Bannister, Neighbourhood Development Co-ordinator, Ashford Borough Council, and Chairman of Ashford and Shepway Dementia Working Group

Panel Discussion (Equalities theme):

- Simon Bannister, Neighbourhood Development Co-ordinator, Ashford Borough Council, and Chairman of Ashford and Shepway Dementia Working Group
- Shaminder Bedi, MBE - Guru Nanak & Milan Day Centres
- Christine Locke, Diversity House
- Roger Newman MBE, Co-Founder, East Kent Independent Dementia Support (EKIDS)
- Viniti Seabrooke, Project Manager – Early Intervention, Alzheimer's and Dementia Support Services (ADSS)
- Rock Sturt, BME Service Development Officer, Alzheimer's and Dementia Support Services (ADSS)

5th April 2011

Interviews:

- Sandie Crouch, Assessment and Enablement Worker, Anna Ramsay, Senior Practitioner, Maidstone and Malling Assessment & Enablement Team and Richard Munn, Assessment and Enablement Manager
- Penny Hibberd, Admiral Nurse and Director of Dementia Services Development Centre South East based at Canterbury Christ Church University

Appendix 2: Written and supplementary evidence

External:

Name	Designation	Organisation (if applicable)
Ansell, Roy		Dementia for Carers Friendship Group
Ayris, Judy	Dementia Outreach Service	Age UK, Canterbury
Bannister, Simon	Former Carer	
Baynard, Maria	Mental Health worker and Former Carer	
Beckinsale, Rev. Pam	Chaplain	KMPT
Bernard, Maurice	Former Carer	
Bettini, Dr Ciao	GP	
Bishop, Jacqueline	Carer	
Bishop, Mr J	Carer	
Bostock, Chris	Chair, Dementia Spirituality Interest Group	DSDC (Volunteer)
Bourne, Rita	Carer	
Britt, Janet	Former Carer	Uniting Carers at Dementia UK (& EKIDS)
Burden, Kay	Training Facilitator and former carer	
Carr, Sue	Professional Standards Officer	Dover District Council
Chandler, Bob	Person with younger onset dementia	
Clay, Lesley	Joint Planning Manager	Canterbury City Council
Cliffe, Sue	Chief Officer	Age Concern, Herne Bay
Connelly, Rosemary		Alzheimer's Society
Cook Adam	Specialist Information Analyst	NHS SE Coast
Cook, Frances	Community Support Worker	KMPT
Donaldson, Tim	Trust Pharmacist, Associate Director of Medicines Management	Tyne & Wear NHS Foundation Trust
Edwards, Jacqueline	Carer	
Edwards, Joan	Carer	
Godfrey, Fiona	Co-ordinator	Caring Altogether in Romney Marsh
Green, Valerie	Carer	
Guss, Reinhard	Consultant Psychologist	Mental Health Services for Older People, Clinical Lead for YOD, KMPT
Hagan, Barbara		Maidstone & Malling Carers Project

Hankey, Jo			NW Kent Carer Support Service
Harman, Charles		Carer	
Hodges, Linda		Carer	
Horstead, Henry		Carer	
Jarvis, Mrs J		Carer	
Jones, Gillian		Former Carer	
Kanagasooriam, David	Dr	GP	
Luck, Maggie			Sunlight Trust
Marion		Former Carer	
Maxted, John		Former Carer	
McArdle, Dawne		Carer	
McBean Priscilla		Training Facilitator and former carer	
Miles, Marie		Consultant	Skills for Care
Newman, Roger		Joint Founder of EKIDS and Former Carer	EKIDS
O'Dell, Michael			Carer's Watch
Oliver, Keith		Person with younger onset dementia	
Oxley, Elayne		Carer Support Worker	NHS Project 'Better NHS Support for Carers', Maidstone & Malling Carers Project
Parlby, Geri		Chairman	REPOD (Rotarians easing the problems of dementia)
Parsonage, Sally		Carer	
Pilgrim, Elizabeth		Dementia Information Service Co-ordinator	Guideposts Trust
Potier, Ellie		Peer Support Group Facilitator	Alzheimer's Society
Read, Tessa		Chairman	EKIDS
Reynolds, Pat and John		Person with dementia and wife/carer	
Roberts, Samantha	Dr.	Clinical Psychologist	Home Treatment Service/Older People's Psychological Services CMHTOP
Rosam, Camilla			Carers First
Salfiti-Hoult, Linda		Carer	
Scanlan, Sue		Director	Invicta Advocacy Services
Sergeant, Kate		Support Manager	Alzheimer's Society Kent and Medway
Silk, Christie		Assistant Officer	Citizens Advice Bureaux

Singh-Murchelle, Argun		British Banking Association
Stewart, Dr Robert	Medical Director	Kent and Medway PCT Cluster
Stirling, Tina	Manager, West Kent	Alzheimer's Society
Turner, Pauline	Carer	
Wharrad, Jacqui	Dementia Pioneer	Dementia UK
Williams, Sonya	Administration Facilitator	Gravesham Access Group
Internal (KCC):		
Buckingham, Sharon	Head of Adult Learning Resource Team	
Cacafranca, Demetria	Projects Officer - SILK	
Critchley, Uta	Emergency Planning Officer	
Fincher, Tricia	Service Development Librarian	
Fordham, Sue	Open Access Manager	
Grant, Janice	Senior Policy Manager	
Hunt, Clare	Administration Officer – Planning and Public Involvement Team	
Kearl, Daren	Community Development Librarian	
Ireland, Susanna	Partnership Development Manager, Community and Social Interest	
Jackson, Lydia	Lydia Jackson Senior Planning Assistant Business Strategy - Adult Social Care Policy	
Munn, Richard	Assessment and Enablement Manager	
Palmer, Beryl	Kent Sensory Services Manager	
Peachey, Meradin	Director of Public Health	
Smith, Sally	Policy Officer	
Vines, Laura	Assistant Policy Officer	

Walton, Georgina Project Manager -
Personal Health
Budgets Project

White, Christine Admin Officer - Adult
Services Learning
Resource Team

Williams, Sue Research Manager
Wyncoll, Keith Equalities Manager

Focus Group Members²

Ayris, Judy (1)		Dementia Outreach Service for Carers, Age UK, Canterbury
Hanson, Emma (1)	Joint Commissioning Manager (Dementia)	Kent County Council
Henderson, Catherine (1&2)	Dr Research Officer	London School of Economics and PSSRU University of Kent
Kanagasooriam, David (1)	Dr GP	Whitstable Medical Practice
Locke, Christine (1&2)		Diversity House
Savitch, Nada (1&2)	Director	Innovations in Dementia CIC
Seabrooke, Viniti (2)	Dr Project Manager	Early Intervention Project, ADSS
Vella-Burrows, Trish (1)	Director	Sidney de Haan Research Centre, Canterbury Christ Church University
Wharrad, Jacqui (1&2)	Dementia Pioneer	Dementia UK

² Focus Group members attended either one or two meetings. Meeting 1 – Input into TOR, Meeting 2 – Input into recommendations.