

DEMENTIA - A NEW STAGE IN LIFE



SELECT COMMITTEE REPORT EXECUTIVE SUMMARY September 2011

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Chairman's Foreword



In a recent national survey, people said they feared the onset of dementia more than anything else including cancer. Yet the Select Committee found that few people understood dementia and its causes and even fewer people were aware that we can all take steps to help prevent it and delay its progress.

This lack of understanding in the general population, and more surprisingly amongst professionals, is making life for both sufferers and carers more difficult, stressful, costly and emotionally and physically draining than it needs to be. Many people said to us "No one listened to me. I was left alone to cope."

We have also heard stories where knowledgeable and skilled workers, volunteers and communities have been able to have a transformational effect, helping people to live well with dementia.

During our work, dementia has become a high profile subject nationally and many other bodies have begun working on improving their dementia services. We hope this report is a workmanlike addition to their knowledge and will help focus attention on the practical improvement which will make a difference.

We have heard many moving stories of carers who have looked after a relative with dementia at quite extraordinary personal cost; they have in many cases given up their right to a private life, career and home, and done so willingly and with love. They deserve our thanks and support

The Select Committee would like to thank all those organisations and individuals who helped us by giving evidence. In particular we would like to thank those who shared their very personal memories.

Trudy Dean

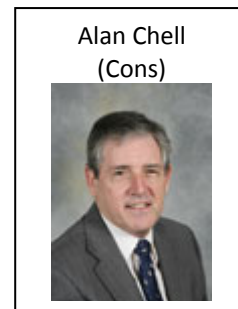
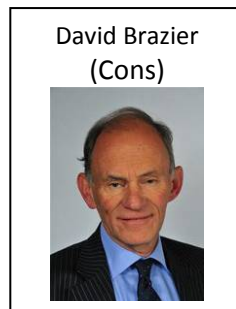
Trudy Dean
Chairman, Dementia Select Committee

I EXECUTIVE SUMMARY

1.1 Committee membership

The Select Committee comprised nine Members of the County Council; seven Conservative, one Labour (co-opted Member) and one Liberal Democrat.

Kent County Council Members (County Councillors):



1.2 Establishment of the Select Committee

- 1.2.1 The Select Committee was established by the Adult Social Services Policy Overview and Scrutiny Committee¹ at the end of 2010 as a result of a proposal submitted originally in 2007 by Members Mrs Trudy Dean and Mr George Koowaree.
- 1.2.2 In the intervening period a National Dementia Strategy was established and Members wished to scrutinise local progress on its implementation, particularly in light of the impact of demographic changes in Kent, concerns expressed by constituents and increased media interest.

1.3 Definitions of Dementia

- 1.3.1 *“The term 'dementia' is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions. Symptoms of dementia include loss of memory, confusion and problems with speech and understanding”².*
- 1.3.2 The National Dementia Strategy: Living Well with Dementia defines it thus:
- “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”.*
- 1.3.3 Defined by a former carer: *“Dementia is a change to a new stage in life. It is not the end of life.”*
- 1.3.4 The most common causes of dementia are given on page 15.
- 1.3.5 Though the presentation and course of different types of dementia varies, the common characteristics noted above become more pronounced over time and the condition is degenerative.
- 1.3.6 Current care approaches focus on extending the period during which people can live well with dementia, supported within their communities or in residential care settings.

¹ now succeeded by the Adult Social Care and Public Health Policy Overview and Scrutiny Committee.

² Alzheimer's Society Online at:

http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=161

1.4 Terms of Reference

- 1.4.1 To examine issues around the '9 Steps' of 'Quality Outcomes' for people with dementia and their carers in Kent³.

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.

- 1.4.2 To identify good practice and innovation in Kent and elsewhere, that could contribute to achievement of the '9 steps'.
- 1.4.3 To identify factors militating against achievement of the '9 steps' and make recommendations for improvements.

1.5 Scope of the review

- 1.5.1 The original draft scope included aspects noted on the next page and those considered to be of most concern to people living with dementia and carers who participated in the review were given greater focus, and hence feature more prominently in this report.

³ Department of Health (2010)

- Stigma
- Awareness-raising among professionals
- Inclusiveness of training, care and support
- Early diagnosis
- Post-diagnosis support
- Carers
- Technology
- Information, advice and signposting
- Decision-making
- Personalisation
- Person-centred care

1.6 Exclusions

- 1.6.1 It was decided at the outset to exclude End of Life Care from the scope, other than from the perspective of decision-making since this aspect of care is not exclusive to dementia and could benefit from investigation by a separate, full and focused select committee review.

1.7 Evidence gathering

- 1.7.1 A list of the witnesses who submitted written evidence is given at Appendix 2 along with the names of professionals who attended one or in some cases two Focus Group meetings to assist the Select Committee prior to decisions about Terms of Reference and Recommendations. A list of witnesses attending hearings is at Appendix 3; details of training and visits carried out as part of the review are given at Appendix 4 and feedback summaries from consultation events on 11th and 15th April are given at Appendix 5.

1.8 Key findings

- 1.8.1 Early diagnosis of dementia is important for a number of reasons. Importantly, it enables the person who is affected to make sense of cognitive or other difficulties they have been experiencing; it enables them to obtain treatment if appropriate for their type of dementia and it is often the means by which they are able to link in to vital sources of local information and support. Being diagnosed early on also buys time for people to discuss and make clear their wishes about the future and to make arrangements for living their life well.

“It makes such a difference if people make their wishes known when they are able to do so and not when they are in a crisis situation.”

1.8.2 Dementia is a condition which is more common in older people and relatively few people under 65 are affected. However, people with learning disabilities (and in particular Down's Syndrome) are living longer and in their 50s and 60s are more likely to develop a dementia than other people of the same age. Due to the relative rarity of younger onset dementia, suitable services and support have been slow to develop in Kent, with the exception of some voluntary sector provision, and as a result the needs of this group are not currently being met.

"If twelve months ago someone had asked me what thoughts came to mind when dementia or Alzheimer's were mentioned I would have described an elderly person who was either being cared for in their own home by a devoted family member or in a residential or nursing home. Since then I have experienced first-hand how mis-informed this view is."

1.8.3 The assessment and diagnosis of people with dementia at Memory Clinics (as directed by NICE guidelines) may not always be the most supportive option e.g. for frail elderly people. There are also gaps in support post diagnosis due to poor communication and a lack of formal shared care arrangements between GPs and specialists. People with dementia who go into hospital may have their medication discontinued because it is not on GP lists. Assessment and diagnosis closer to home could contribute to reduced stigma; improve the rates of diagnosis overall and improve outcomes for more people with dementia and their carers.

"Mum had a fall and fractured her hip. She went into the William Harvey Hospital. The staff ignored me when I tried to speak to them about her dementia medication. Her GP hadn't recorded it so the hospital thought that she wasn't on any medication. We found it hard to get information when she was in hospital."

1.8.4 The stigma associated with dementia is steadily reducing as people become more aware of the condition. It is important to keep up the momentum that has built up in awareness-raising. Reducing stigma will ensure that people with dementia are treated with dignity and respect in their communities. It will also mean they are less afraid to seek support and help. Some Black and Minority Ethnic (BME) communities need a different approach to ensure that stigma is addressed and families are not left isolated and unsupported. Ensuring that young people have a good understanding of dementia could reduce the level of stigma people will experience in the future; help to build compassion in communities and contribute to a more caring and empathetic workforce in the future.

“Image is everything. Minority Groups need to be confident that when they raise issues they will be heard.”

- 1.8.5 Public health messages have an important role to play in persuading people to adopt healthier lifestyles that could reduce the chances of their developing a dementia in the future. The national programme of Health Checks, as it is established in Kent, could reinforce messages about healthy lifestyles and help to identify people at risk of a dementia in future. It could also help to identify people at the early stages of dementia and link them to appropriate treatment and support earlier than is currently achieved in Kent.

“We are at the tipping point of public awareness”.

- 1.8.6 Voluntary Sector organisations provide invaluable specialised support for people with dementia and their carers and this will become increasingly important as fewer in-house (council provided services) are available. There is currently an uneven distribution of services across the county and commissioners of health and social care services for dementia will have an important role in ensuring everyone in Kent who has a dementia can access support locally.

“We are looking at the possibilities of new groups as some have become so popular that they are outgrowing their venues. At our newest group for those with Younger Onset Dementia last evening we had nine couples including three new couples . . .”

- 1.8.7 Home care support is not currently set up in a way that acknowledges the particular problems and challenges faced by people with dementia, whether or not they have a diagnosis. The level of dementia awareness and training of the care workforce needs to be raised overall and in order to achieve this, the Select Committee proposes that KCC assessment and enablement workers should have a higher level of dementia training. Furthermore, dementia training should be a requirement in contractual arrangements with providers. The Select Committee believes that provision of specialist as opposed to generic services is not, in itself, a solution but an increase in the availability of highly specialised voluntary sector dementia support in Kent will ensure that more people purchasing services can choose the level of support that they need. It could also enable different models of homecare provision (e.g. combining personal budgets at local level) to be tested.

“We often find carers deciding it is easier to struggle on coping alone rather than put up with different and often poorly trained workers coming into the home.”

1.8.8 Residential care services, whether specialised to dementia or generic can improve the lives of people with dementia, firstly, if the living environment incorporates physical design features in line with current best practice and secondly if well-trained staff can ensure there are meaningful activities and positive interactions for people, helping to retain skills and pursue interests, faiths and important relationships.

1.8.9 Carers for people with dementia play an important role which needs to be better recognised and acknowledged. If people with dementia are expected to live well and safely at home, carers too must be well supported. Carers for people with dementia need respite appropriate to their needs; and ready access to the information they need to help them in their caring role. The important relationship between the carer and cared for person must be protected and supported. Carers must also be able to enjoy their own lives. Carer support organisations would welcome a ‘9 Steps for Carers’ which acknowledges the crucial role that carers play in supporting people living with dementia. Carers across the county are now able to access comprehensive ‘Confidently Caring’ training to support them in their role.

“What happens when a carer gets ill – carers neglect themselves and miss even flu jabs as they have no-one to help.”

1.8.10 The dementia care pathway in the future should be one which acknowledges the high level of social care needs that the condition demands. The particular health needs of people with dementia must be met in whichever setting they are living. The available funding should be identified and directed towards preventative (early intervention) services so that people with dementia and their carers can access a range of support to improve health and wellbeing. This should include positive and educational activities; social support, including memory cafes and peer support; advocacy services; crisis and emergency support and planned respite.

“It is only because we can see his house, coupled with the technology we now use, that he is able to remain in the home he has lived in for 55 years.”

“The Dementia Advocacy team were a godsend. To have an independent person to represent D’s needs and rights was a huge relief, and made me feel less of a lone (and emotionally involved) voice.”

1.8.11 Professionals in health and social care fields must be made more aware of dementia, its effects on people with the condition and their carers and the support that is available. Professionals must ensure they integrate their planning and their records as well as their day to day working so that people with dementia and carers are better supported. The Health and Wellbeing Board can play an important role, ensuring that this integrated working takes place at all levels. A range of professionals from different sectors including Kent Police can also contribute to better safeguarding for people with dementia and their carers.

“None of the services are not doing their job but what they are not doing is doing it together.”

1.8.12 People with dementia, their carers and former carers can play a vital role in directing the development of services and support including through Local HealthWatch and potentially through membership of any dementia advisory group set up in relation to the Health and Wellbeing Board.

‘Co-production is an idea whose time has come. The idea, put simply, is that people’s needs are better met when they are involved in an equal and reciprocal relationship with professionals and others, working together to get things done.’

1.8.13 There is an increasing body of research and knowledge about dementia. Dementia service commissioners and providers have the opportunity to work with academic colleagues to develop new services and test models of service provision developed with and by people with dementia and their carers. This will ensure that future services and support are better tailored to meet their needs.

1.9 RECOMMENDATIONS⁴

DEMENTIA IN KENT

R1

That a business case is developed in Kent for shared care prescribing arrangements for dementia medication and that GPs are encouraged to be more proactive in reviewing all people diagnosed with dementia, regardless of whether dementia medication is indicated. (p50)

R2

That in disposing of KCC buildings, the options for Community Asset Transfer are proactively explored to maximise the opportunity for voluntary sector dementia respite and day services. (p54)

R3

That KCC seeks to work with Dementia UK and relevant health organisations including GP practices in Kent to explore ways of widening access to the Admiral Nursing Service in Kent so that more people with dementia and their carers have access to a named, specialist contact. (p57)

SUPPORTING EARLY DIAGNOSIS BY RAISING AWARENESS AND REDUCING STIGMA

R4

That, to improve the rates of early diagnosis of dementia in Kent, KCC:

- works with colleagues in Public Health, the Voluntary Sector, community and faith groups to raise awareness (and dispel stigma) about dementia in the general population and among particular cultural groups, encouraging the use of positive and inclusive language and images in communications about dementia.
- works with the Alzheimer's Society to develop a '10 signs of dementia' poster (which distinguishes between signs of concern and normal signs of ageing).
- considers whether media/publicity could help to raise awareness about dementia, such as:

⁴ Page numbers refer to main report

Memory problems that interfere with daily life?

Inability to plan and solve problems?

New problems with speaking or writing?

Difficulty completing familiar tasks?

See your doctor and discuss ways to get advice, information and support

- presses for the inclusion of an appropriate dementia screening tool in the NHS Health Checks programme in Kent (and adherence to relevant NICE guidance). (p79)

R5

That, to ensure young people have a good understanding of dementia, KCC:

- ensures libraries in Kent have books which explain dementia to children of different ages and encourages schools to do so
- seeks to fund a youth project to create a DVD, raising awareness about dementia and encouraging inter-generational support, which could be shown in Kent schools. (p82)

SUPPORTING CARERS AND CARING RELATIONSHIPS

R6

That KCC acknowledges and highlights the perspective of carers (and former carers) for people with dementia in a '9 steps for dementia carers' for inclusion in the next Kent Carers' Annual Report. (p85)

R7

That KCC encourages the commissioning of a variety of early intervention measures in order to reduce avoidable, inappropriate and expensive hospital admissions for people with dementia, to improve the quality of life and outcomes for a greater number of people with dementia and carers and that commissioning should include:

- Implementation of a pilot Shared Lives scheme for people with dementia, in co-operation with PSSRU Kent University, which develops the current Adult Placement Scheme and explores whether the management of personal budgets by voluntary sector service providers could help to provide more person-centred respite, for example, for people in rural areas, using the Shared Lives Model.
- Independent advocacy services for people with dementia in East and West Kent.

R8

That KCC seeks to promote greater awareness of Lasting Powers of Attorney (LPA) and considers whether a service could be offered by KCC Legal Services in this regard and that KCC supports the work of the British Banking Association to improve training for staff on LPA in order to minimise stress experienced by carers for people with dementia in organising finances. (p97)

R9

That KCC works with Kent Police and relevant health organisations in order to ensure that there is proactive support for and appropriate responses to carers who may be experiencing domestic violence as a result of dementia-related aggression in a loved one. (p101)

R10

That KCC extends the successful Telecare pilot work by evaluating how different types of assistive technology can support people with dementia to live safely and securely at home and in particular to assist with 'safer walking'. (p104)

INFORMATION AND SIGNPOSTING

R11

That KCC ensures that people living with dementia and their carers have access to good quality, well maintained information on local services and support in Kent and in their local area and that:

- printable, district level information is made available through links on DementiaWeb.
- KCC works with relevant health organisations and partners in the voluntary sector to ensure that this standard information 'set' is known to/made available through local authority offices, Gateways, Citizens Advice Bureaux, dementia and carer support organisations and in particular GP surgeries.
- as well as signposting to local groups offering dementia support, DementiaWeb should provide information about Adult Education opportunities and details of the Health Referral Scheme (50% discount on courses), and Library services for people with dementia.
- there is a consistent approach to the provision of information and signposting by KCC in response to enquiries regarding people with dementia who are self-funded, ensuring that all enquirers are made aware of DementiaWeb and the local information guides. (p111)

R12

That KCC and Health Commissioners should ensure that every Kent district or borough has at least one memory cafe as well as peer support for people with dementia. That KCC should promote the grass roots development of a network of memory cafes and peer support by engaging local groups such as Rotary, U3A, Older Person's forums, Carer Support Groups and Neighbourhood Watch; encouraging them to apply for funding through Members' Community Grants. (p115)

DEMENTIA CARE PATHWAY – FUTURE STRATEGY FOR KENT

R13

That in establishing and developing the 'core offer' of services and support for people with dementia and their carers, KCC and NHS Dementia Service Commissioners build on existing links with the academic sector (particularly the Dementia Services Development Centre at Canterbury Christ Church University and PSSRU at the University of Kent) to maximise research opportunities and ensure that the development of the dementia care pathway in Kent is informed by evidence and best practice. (p120)

R14

That, given the high proportion of undiagnosed dementia in Kent, '2nd level' training in dementia should be compulsory for all KCC assessment and enablement workers; basic dementia awareness training should be strongly encouraged for other KCC staff engaged in dementia support work and a requirement for an appropriate level of dementia training should be reflected in contractual arrangements with providers. (p121)

R15

That KCC (through the Health and Wellbeing Board, where appropriate):

- encourages GP practices to invite voluntary sector dementia support organisations to protected learning sessions to raise awareness among clinical and non-clinical staff about dementia and the local support available for people with memory problems.
- focuses on maximising KCC's role in the training and development of the social care workforce to ensure that safety and quality of care for people living with dementia are given the highest priority.
- encourages the commissioning of joint education and training for health and social care professionals including General Practitioners, on dementia, to support integrated working in the future.

- encourages greater awareness among hospital staff in Kent about when to engage with liaison nurses to minimise admissions, reduce lengths of stay, ensure dignified care and speed up discharges to appropriate locations for people with dementia in order to minimise distress and contribute to cost savings.
- encourages relevant health organisations, including GP practices and partners in the voluntary sector to identify opportunities for pooled health and social care funding of community based care co-ordinators (see recommendation 2) and that personalised multi-agency care plans can be readily accessed by professionals providing care and support to people with dementia at home and during transitions of care.
- Identifies as a matter of urgency the approximate current spend on dementia by all agencies and models the change in spend between providers as diagnosis rates improve, the social care model is implemented and there is a change in use of acute services. This will provide a benchmark for the development of services and a context for assessing the value both in cost and quality of provision of pooled budgets and preventative services. (p128/9)

R16

That KCC considers whether a separate Kent & Medway strategy for Younger Onset Dementia is required to ensure that the needs of this group are met and that any future dementia strategy or plan:

- takes account of the particular circumstances experienced by a younger age-group and the development of appropriate services and support based on evidence and best practice
- includes an assessment of the likely impact of increased numbers of people with learning disabilities having dementia in the future
- is proactive in mapping where support and services will be needed. (p130)

R17

That people living with dementia and their carers are enabled to play a central role in encouraging integrated services and deciding how best to support people with dementia and their carers in Kent including through HealthWatch and its links to the Health and Wellbeing Board and the GP commissioning bodies. (p132)

“... by taking part in things like this to raise awareness, it gives me a purpose in life. It makes me feel like I am doing something worthwhile and helping others in my situation while I still can. Thank you for listening.”