DEMENTIA - A NEW STAGE IN LIFE

SELECT COMMITTEE REPORT

September 2011

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Cover photos: boat trip to offshore windfarm and forts; strawberry tea; Christmas celebrations and Memory Club with reminiscence session (courtesy of EKIDS); Circle Dancing workshop for practitioners at DSDC Conference 2011 (courtesy of Cynthia Heymanson); Age UK’s new Hazell Nevill Dementia Care Unit at Reculver (visit); day services (courtesy of ADSS)

Contents

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):

Ann Allen
(Cons)

David Brazier
(Cons)

Alan Chell
(Cons)

Leslie Christie
(Lab)

Trudy Dean
(Lib Dem)

John Kirby
(Cons)

Steve Manion
(Cons)

Ken Pugh
(Cons)

Avtar Sandhu
(Cons)

1.2 Establishment of the Select Committee

1.2.1 The Select Committee was established by the Adult Social Services Policy Overview and Scrutiny Committee[1] 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 21.

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.

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[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[3]

1.4.1 To examine issues around the ‘9 Steps’ of ‘Quality Outcomes’ for people with dementia and their carers in Kent[4].

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.

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[3] Members agreed to base the Terms of reference on the ‘9 Steps’ following a suggestion made by Jacqui Wharrad, Dementia Pioneer for Dementia UK at a professionals’ Focus Group meeting.

[4] 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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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 RECOMMENDATIONS

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:

  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 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. (p133)

2 BACKGROUND AND INTRODUCTION

2.1 Causes of Dementia[5]

2.1.1 There are numerous diseases and conditions that can result in a dementia, the most common of which are:

- Alzheimer's disease
- Vascular disease
- Dementia with Lewy bodies
- Fronto-temporal dementia (including Pick's disease)

2.1.2 **Alzheimer’s Disease** is named after the German neurologist who discovered it. It involves changes in brain structure when 'plaques' and 'tangles' develop and changes in brain chemistry as there are fewer chemical messengers to provide vital links between the brain’s nerve cells, causing them to die and resulting in a decline in cognitive ability. Treatment[6] can prevent the breakdown of the chemical messenger in the brain and alleviate some symptoms, but the disease is progressive and there is as yet no cure. Between 10% and 50% of people with Mild Cognitive Impairment (inability to think clearly or remember things) progress to Alzheimer’s Disease. Health, age, environmental, genetic and diet-related risk factors are known to play a part in its development but as yet a specific cause is unknown. The greatest risk factor is age, though genetics are significant when the onset is at a younger age (under 65). Carriers of the ApoE4 gene variant are more likely to develop it as are people with Down’s Syndrome who live to their 50’s and 60’s. *Specific* environmental factors have yet to be identified.

2.1.3 **Vascular Dementia** can result if the brain is not supplied with oxygenated blood leading, in time, to brain cell death. Symptoms can begin suddenly, such as after a stroke, or over a longer period. Preventing and treating high blood pressure, heart problems, high cholesterol and diabetes, which all affect the health of blood vessels, is therefore important. Though some symptoms are similar to those of other types of dementia, common problems in vascular dementia are concentration and communication problems, depression , stroke symptoms such as paralysis, memory problems, symptoms remaining at a constant level and then suddenly deteriorating, epileptic seizures and periods of acute confusion. Less common problems include hallucinations, delusions, wandering (and becoming lost), physical/verbal aggression, restlessness and incontinence. Vascular dementia itself has various types but primarily is

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[5] Alzheimer’s Society (2011) [Online]

[6] with Acetyl Cholinesterase Inhibitors

caused by stroke, small blood vessel disease or a combination. People can have mixed dementias, e.g. Alzheimer’s disease and Vascular dementia.

2.1.4 **Dementia with Lewy bodies (DLB**) is named after the small spherical protein structures that develop inside nerve cells which, in the brain, cause tissue to degenerate. As with Alzheimer’s Disease, DLB develops over several years but memory may be less affected and symptoms of attention/alertness are more significant. Spatial awareness is likely to be affected and people with DLB may find it difficult to plan ahead and co-ordinate their thinking. Symptoms are otherwise akin to those of Alzheimer’s and Parkinson’s disease, the latter including slowness, muscle stiffness, trembling limbs, a shuffling gait, loss of facial expression and changes in voice strength and tone. Other symptoms peculiar to DLB are:

- hallucinations, often of people or animals
- fluctuating abilities
- sleepy days and restless, disturbed nights
- faints, falls, or 'funny turns'.

2.1.5 **Fronto-temporal dementia** (including Pick's disease) can be caused by frontal lobe degeneration and motor neurone disease. It is characterised by changes in personality and behaviour, rather than memory since the areas of the brain affected are associated with behaviour, emotion and language. Though fairly uncommon overall, it is one of the most common causes of younger onset dementia. Language difficulties could include problems finding the right words, lack of spontaneous conversation, using too many words or reduced, even loss of, speech. Common behavioural symptoms are:

- a lack of insight and empathy
- becoming either extrovert or introverted
- behaving inappropriately (e.g. being rude, tactless)
- losing inhibitions (e.g. sexual behaviour in public)
- becoming aggressive
- being easily distracted
- behaving compulsively

There may also be changes in eating habits, such as overeating. The disease progresses over a period of around 2-10 years and in the later stages symptoms resemble those of Alzheimer’s Disease. Up to 50% of cases have a genetic basis and the genes tau and progranulin have been implicated so far. The cause(s) of the non-genetic types are not known.

2.1.6 **Rarer dementias** include those from dementia from progressive supranuclear palsy, Binswanger's disease, HIV and AIDS, Creutzfeldt-Jakob disease (CJD) and Wernicke-Korsakoff syndrome which is often caused by prolonged heavy drinking and the resulting Thiamine (Vitamin B1) deficiency. People with multiple sclerosis, motor neurone disease, Parkinson's and Huntington's diseases may also be more at risk of developing dementia.

2.1.7 Regardless of the cause of the dementia it is a condition which profoundly affects people's lives and those of their families.

2.2 Younger Onset Dementia

2.2.1 Younger onset dementia relates to people under the age of 65. It is relatively rare with a national prevalence of 2.2% but the prevalence among people with a learning disability is higher.

2.2.2 It is important that professionals working with people with a learning disability are vigilant in spotting early signs of dementia and its identification may be more difficult in those people whose communication is non-verbal. 20% of people with a learning disability have Down's Syndrome and this group of people have a considerably higher risk of developing dementia than the general population, more markedly by the time they reach their 50s. Figure 1 below shows that over half of the people with Down's Syndrome who reach the age of 60 will have a dementia (often Alzheimer's Disease) compared with very few people (under 1% at age 59) in the general population.

Figure 1: Prevalence of people with Down's Syndrome, compared with people with other forms of LD and the general population[7]

Age	Down's Syndrome	Non-Down's LD	General Population
30-39	2.0%		<0.2%
40-49	9.4%		<0.2%
50-59	36.1%	13% (at 50+)	<0.2%
60-69	54.5%	22% (at 65+)	<2.0% (at 65-69)

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[7] Alzheimer's Society (2010)

2.3 International context

2.3.1 Men and women all over the world are affected by dementia; primarily older people but also affecting under 65s. Some people's genetic background puts them at higher risk. International data is difficult to compare, as countries have different healthcare priorities and methods of data collection can vary considerably. However, one study has estimated the number of people worldwide living with dementia at 24.3 million.[8]

2.3.2 From comparisons between different countries we know that the rate of dementia in the community is fairly constant. England's population structure is changing (towards having more older people) at a similar rate to France, Netherlands, Scotland and Wales while Australia, Canada, New Zealand, Northern Ireland and the USA will experience a faster increase. The proportion of older people in the population is expected to increase, but more slowly, in Denmark, Germany, Italy, Japan and Sweden. Since the rate at which dementia occurs in the community appears to be similar, countries with a greater proportion of older people in the population can be expected to have more people living with dementia in the future and a greater demand for services and support.

> ***'Prevalence rates of dementia appear to vary little between countries and the condition affects all socioeconomic groups'.***[9]

2.3.3. Countries have different approaches towards caring for and supporting people living with dementia but there is a general trend towards older people staying in their homes for longer, rather than moving into care homes. Data recorded during 1997-2006 showed that (as a percentage of the over 65 population) the total number of people in care homes ranged from only 2% in Italy, to 11% in Norway. In England 5.5% of people aged over 65 were living in care homes (in 2006).[10] As might be expected there was also a variation in the proportion of older people receiving home care, ranging from 2.4% in Northern Ireland to 25% in Denmark.[11]

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[8] Ferri CP et al. (2005)
[9] NICE (2009)
[10] Knapp M et al (2007)
[11] Ibid

2.4 National context

2.4.1 Recent reports and research have highlighted the shortcomings in the current provision of dementia services in the UK and the challenge to society that it presents now and in the future. There are currently almost 822,000 people in the UK with dementia, of whom approximately 669,000 live in England. Costs to the UK economy are £23 billion a year including health and social care, lost productivity and informal care[12]. In 40 years' time, the number of people with dementia in the UK will rise to 1.7 million, with the associated costs set to more than double.[13]

2.4.2 Since the rates of diagnosis are improving and people are living longer, the prevalence figures for dementia in the UK are increasing. Figure 2 below shows clearly the impact of greater longevity on the number of people likely to have the condition in the future. For example, the prevalence of dementia among females aged 65-69 is only 1.1% but in the 95-99 age group it is 36%, so for every 100 women aged 95-99 in the UK 36 will have a dementia.

Figure 2: EURODEM UK prevalence rates (diagnosed and undiagnosed dementia)[14]

Age group, years	Male	Female	Average M/F
30-59	0.16%	0.09%	0.13%
60-64	1.58%	0.47%	1.03%
65-69	2.17%	1.10%	1.64%
70-74	4.61%	3.86%	4.24%
75-79	5.04%	6.67%	5.86%
80-84	12.12%	13.50%	12.81%
85-89	18.45%	22.76%	20.61%
90-94	32.10%	32.25%	32.18%
95-99	31.58%	36%	33.79%

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[12] Alzheimer's Research Trust (2010)
[13] Foresight (2011)
[14] Ibid

2.5 Recent Milestones in the development of dementia policy in England:

- **National Audit Office ’Improving services and support for people with dementia (2007)**

This report highlighted that health and social services gave dementia too low a priority; that too few people were diagnosed; that diagnosis was not made early enough and that cost-effective interventions were not being made available. It found that there was poor awareness and understanding of dementia (including among front line staff) and likened dementia now to cancer in the 1950s when few people were treated or told they had the disease in case it caused distress. It found that failure to diagnose and treat dementia led to extended hospital stays but that having a diagnosis of dementia also caused delayed discharges and escalating costs. Regarding the majority of people who live with dementia in the community, the report identified that they were often cared for by carers who themselves lacked support or in care homes where less than 28% of the beds were for specialist dementia care.[15]

Key conclusions and recommendations of the report were that:

- improvements were needed to health and social care management of dementia and the way they work together
- awareness needed to be raised among health and social care professionals
- diagnosis, early intervention and support in the community needed to be improved

- **Improving Services and Support for people with Dementia - 6th report of session 2007-08 (2008)**

Following on from this report of the House of Commons Committee of Public Accounts, in 2008 the Department of Health commissioned a report to look at medication of dementia patients in England.

- **Banerjee, S ‘The use of antipsychotic medication for people with dementia: Time for action’ (2009)**

Professor Sube Banerjee’s 2009 report estimated that only one in five of the 180,000 people with dementia prescribed with antipsychotics benefited from the treatment each year. He also reported that this medication led to additional strokes (half of them severe) and other similar events, and 1,800 more deaths than would normally be expected. Prof. Banerjee recommended a careful consideration of risk versus benefits and a reduction in prescribing by two-thirds over three years. He also recommended the use of non-pharmaceutical interventions to treat dementia-related behavioural problems (which antipsychotics are primarily used to control).

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[15] It also highlighted the limitations in End of life care for people with dementia.

- **Department of Health, ‘Living well with dementia: a national dementia strategy’ (2009)**

This report, often referred to as the NDS, was the first ever English national strategy on dementia and set out the previous government’s 5-year plan to help develop services for people with dementia and their carers regardless of age, ethnicity or social status. It had 17 Objectives (Appendix 6) and three key themes of improving knowledge/reducing stigma; early diagnosis and support and service development. A reduction in the use of antipsychotics for dementia patients is now regarded as the ‘fourth theme’.

- **National Audit Office, ‘Improving dementia services in England: an Interim report’ (January 2010)**

This report was very critical of the level of implementation that had taken place since publication of the NDS in 2009. It found that despite dementia being a national priority, implementation was without the ‘levers or urgency’ needed and value for money was as a result, at risk.

- **NICE ‘10-point Quality Standard on Dementia care’ (2010)**

These recommendations to government were published at the end of June 2010. (Appendix 7) and standards related to care provided by health and social care staff for people with dementia in hospitals, the community and home-based, group, residential or specialist settings. The Standard applies to the whole dementia care pathway and requires that integrated services are commissioned and coordinated across relevant agencies.[16]

- **Department of Health ‘Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy’ (2010)**

The coalition government affirmed its commitment to the National Dementia Strategy by its publication, in September 2010 of a revised and outcome-focused implementation plan to replace the plan originally put forward in 2009. It has four new priority areas:

- Good-quality early diagnosis and intervention for all
- Improved quality of care in general hospitals
- Living well with dementia in care homes
- Reduced use of antipsychotic medication

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[16] The Quality Standard was developed as a follow up to a 2006 clinical guideline report (42) by NICE and the Social Care Institute for Excellence (SCIE)

- **Alzheimer's Research Trust, Dementia 2010 (2010)**

This report, produced by the Health Economics Research Centre at the University of Oxford, investigated the prevalence, economic cost and research funding of dementia compared with cancer, coronary heart disease (CHD) and stroke. It found that the annual cost of dementia to the UK economy was £23 billion; more than the combined cost of cancer (£12b) and CHD (£8b). It also found that for every £1 million in health and social care costs, £4,882 is spent on dementia research compared with £8,745 on stroke research, £73,153 on CHD research and £129,269 on cancer research.

2.6 The broader context of health and adult social care

2.6.1 The development of policies and strategies specific to dementia has been taking place against a backdrop of changing attitudes towards health and adult social care as a whole. The government Health and Social Care White Paper, "Our Health, Our Care, Our Say", published in January 2006, built on the 2005 Green Paper "Independence Wellbeing and Choice". Together, these documents set out a 15-year vision and strategy for adult health and social care which put the individual at the heart of service delivery, and signalled a radical shift away from the concepts of 'welfare' and 'being done to'. Also coming to the fore was the role the community could play in supporting people to live independently. Both papers addressed the issue of risk and how to minimise it while enabling people to live as normal a life as possible.

2.6.2 'Putting People First', published in December 2007 focused on four key areas: universal services, prevention and early intervention, choice and control and support closer to home. Lord Darzi's review of the NHS, 'High Quality Care for All'[17] emphasised quality rather than quantity of care, continued the themes of prevention, quality and innovation and balanced the need for locally responsive services with the need for a consistent standard of care. Importantly it stated that everyone with a long term condition should have a personalised care plan which all those involved in the care partnership could contribute to. The right of all health care recipients to compassion, dignity and respect is enshrined in the new NHS Constitution.

2.6.3 Equalities issues in health and social care were addressed in 'Culturally Competent Care'; guidance for care managers produced in Kent and launched in the House of Commons in 2002 and this has now been developed by KCC in Race, Faith and Culture – a Support Toolkit which develops the themes from Putting People First in the context of communities. Dignity, respect and cultural competence should be the mainstay of all health

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[17] Darzi Review (2008)

and adult social care services and support and these aspects were highlighted as being of prime importance to people with dementia and their carers (as well as professionals) who gave evidence to this review.

2.6.4 ‘Quality Outcomes’ (see 2.5) considered the National Dementia Strategy in the context of the coalition government’s plans for health and social care outlined in the White Paper ‘Equity and Excellence: Liberating the NHS’; and changes to the National Health Service outlined in the consultation document ‘Liberating the NHS: Transparency in outcomes – a framework for the NHS’. Changes are being driven forward by the QIPP (Quality, Innovation, Prevention and Productivity) process which is a framework for optimising quality in the NHS while attaining the substantial efficiency savings needed.

2.6.5 Funding for adult social care is likely to undergo further radical changes in light of the findings of the Dilnot Commission on the future funding of care and support which made its recommendations to government in July. The report’s findings could lead to more equitable funding for social care, with a capping of costs to be borne by individuals set somewhere in the range of £25.000-£50,000 at a cost of £1.3-2.2b. Also proposed is raising the threshold for means tested support from its current level of £23,250 making more people eligible for free care. A further proposal is for a statutory duty to be placed on local authorities to provide information, advice and assistance services.[18]

2.7 Regulation of Health and Adult Social Care

2.7.1 The Care Quality Commission (CQC) is the body responsible for the registration, licensing and monitoring of care standards. In addition, since October 2010, Health and Adult Social Care services in England have a legal responsibility to meet essential quality and safety standards and the CQC can take action against organisations who are not meeting the standards. The CQC provide separate guidance leaflets which are available online on regulation of NHS hospitals, care homes and agency care provided at home. What the CQC deems people should be able to expect from health and adult social care services is summarised below:

- to be involved and told what’s happening at every stage of care
- care, treatment and support that meets people’s needs
- to be safe
- to be cared for by qualified staff
- that care providers will constantly check the quality of their services[19]

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[18] Dilnot Commission (2011)
[19] Care Quality Commission (2011)

2.8 Commissioners and Providers

2.8.1 In order to understand the changing landscape of health and social care it is useful to think of the organisations involved in terms of whether they are commissioners or providers of services (some are both). The trend within Local Authority Adult Social Care including within KCC is to reduce in-house social care provision and move increasingly towards a commissioning-only role. This results from considerable reshaping of health and social care policy which will fundamentally change the way the NHS, Local Authorities and GPs commission services. GPs will be responsible for much of the commissioning previously carried out by the Strategic Health Authorities and Primary Care Trusts and voluntary sector organisations will play a much greater role in the provision of services. In future 'Any Qualified Provider' may provide healthcare (part of NHS moves to extend patient choice) and these may also be referred to as Health Provider Organisations (HPOs).

2.9 Health and Wellbeing Boards

2.9.1 The sweeping changes to the National Health Service set out in the much debated Health and Social Care Bill[20] include the setting up of Health and Wellbeing Boards (HWB) by Local Authorities. One of the key roles of HWB will be to encourage integrated working by providers of health and social care services and those who 'arrange for them' i.e. commissioners. Integration will focus on the way different sectors of health care work together e.g. primary (GPs) and secondary care (specialists) as well as how health and social care work together to provide services.

2.9.2 According to the Kings Fund, greater integration: ''… *offers the most promising approach to improving patient care and meeting the key future challenge facing the NHS – demographic change and supporting the increasing number of people with long-term conditions*.'.[21]

2.9.3 The HWB will bring together GPs, the Local Authority (Members and senior officers) and (in a two-tier authority) District Councillors and, since recent amendments to the Bill, will have an enhanced role in encouraging partners to work together and pool budgets.

2.9.4 Involvement in Health and Wellbeing Boards will enable elected Members to contribute to improved integration through the strategic co-ordination of commissioning across health and social care. They will be able to ensure that community priorities are at the fore, through links with Locality Boards or equivalent local arrangement.

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[20] Introduced in January 2011 and reaching its 3rd Reading in September

[21] The Kings Fund (2011)

3 DEMENTIA IN KENT

3.1 Demographics – a changing population

3.1.1 The issue of dementia and improving outcomes for people living with it is particularly significant for Kent since the increase in the number of people affected will be faster in Kent than it will be elsewhere. The population is increasing 4% faster than in the country as a whole and over the 25 years from 2008, the population of the KCC area is projected to increase by 22% (310,300 people). This means there will be 1,712,000 residents by 2033. During that same period the number of people aged 65 and over in Kent is projected to increase by 67%. This trend towards an older population is also more pronounced in Kent where the changes will take place 2% faster than in England as a whole. The number of people aged 65 and over in Kent's population over the next 20 years is shown in figure 3 below. Figure 4 on the next page shows the number of people in Kent aged over 65 who are predicted to have dementia.

Figure 3: Population by Age in Kent[22]

Age	2010	2015	2020	2025	2030
65-69	73,700	92,500	81,400	90,100	106,000
70-74	61,400	69,400	87,500	77,500	86,300
75-79	49,700	55,500	63,300	80,200	71,700
80-84	37,400	41,000	47,300	54,700	69,700
85-89	24,000	26,100	30,200	36,400	43,000
90+	12,000	15,700	19,600	25,200	33,300
Total Population aged 65 and over	258,200	300,200	329,300	364,100	410,000

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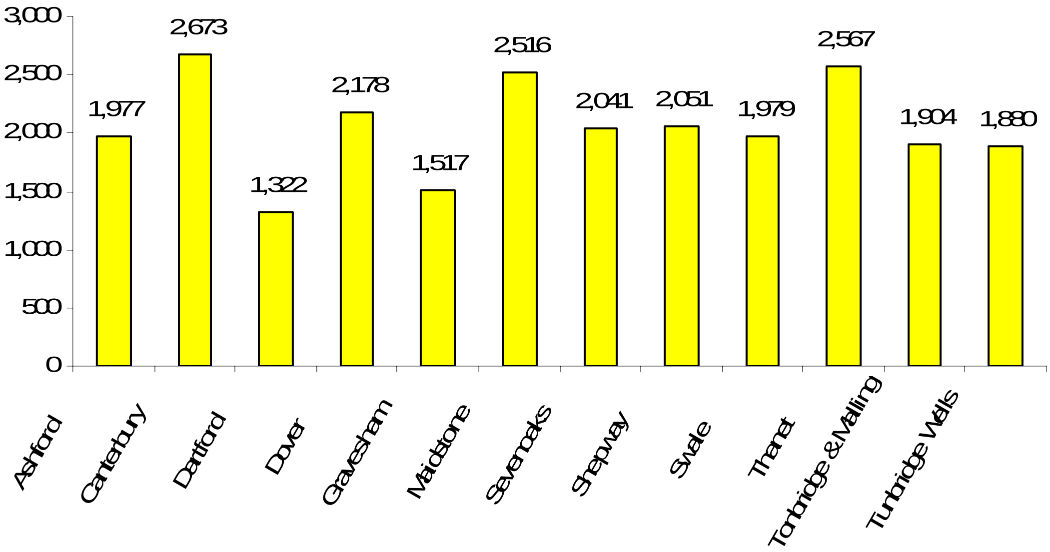
[22] POPPI (2011)

Figure 4: The number of people in Kent aged 65 and over predicted to have dementia[23]

Age	2010	2015	2020	2025	2030
65-69	916	1,147	1,006	1,120	1,313
70-74	1,677	1,896	2,387	2,115	2,357
75-79	2,918	3,243	3,709	4,699	4,199
80-84	4,513	4,901	5,620	6,520	8,294
85-89	4,888	5,244	6,017	7,223	8,518
90 and over	3,617	4,680	5,824	7,465	9,848
Total population aged 65 and over	18,529	21,110	24,563	29,141	34,528

3.1.2 Figure 5 below shows that by 2020 Canterbury will have the greatest number of people with dementia (2,673) and Dartford the fewest (1,322).

Figure 5: Chart showing the number of people in each Kent District aged 65 and over predicted to have dementia by 2020[24]



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[23] POPPI (2011)

[24] Ibid

3.1.3 Including people under the age of 65 there are currently estimated to be around 21,000 (some estimates are as high as 24,000) people living with dementia in Kent & Medway and in 20 years time this figure is expected to rise to around 40,000.

3.1.4 Kent is a county of increasing ethnic and cultural diversity and so all services and support (regardless of who provides them) including those for people with dementia must be sensitive to differing perspectives and capable of responding to the needs of diverse communities, putting targeted strategies in place where they are required.

3.1.5 The number of people in Kent formally diagnosed with dementia is estimated to represent considerably less than half of the total number of people who are living with the condition. This is unsatisfactory since diagnosis of dementia early on in its progression is crucial so that people can establish contact with appropriate support services. Receiving support early on helps people to avert crises and helps them to make important choices and decisions about the future. People who may experience particular stigma associated with dementia, including those from BME communities, are less likely to seek diagnosis. This is discussed further in section 4 of this report.

3.1.6 Across all age groups 40% of people with a dementia have co-morbidities (other medical conditions or disabilities)[25] and over 50% of people aged 75 have a chronic condition typical of older age.[26]

3.2 Younger Onset Dementia in Kent

> ***"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."***
> Keith Oliver – written evidence

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[25] Dr John Ribchester, Senior Partner, Whitstable Medical Practice – Hearing 23rd March 2011

[26] Dr Graham Stokes, Director of Dementia Care, Bupa Care Homes – Presentation 7th June, Ashford

3.2.1 The two Dementia Joint Strategic Needs Assessments (JSNAs) for East and West Kent state that the key components of services for people with younger onset dementia (YOD) should be the same as those for older people. The JNSAs acknowledge that people with YOD may have additional needs related to work, children, being fit and active, having financial commitments and the likelihood of having a rarer form of dementia.

3.2.2 There are approximately 500 people with young onset dementia in Kent. For this group of people services are 'out of sync' i.e. they are designed for the majority of people with dementia who are around 20-30 years older. This also impacts on services aimed at carers. The particular gaps that have been identified in evidence are:

- Early preventative support at home
- Lack of specialism in dementia/YOD
- Specialist Day Services
- Specialist (or any) Respite
- Specialist Residential services
- Age appropriate facilities and activities for people with YOD[27]

> ***"Our involvement with Carers of people with younger onset dementia is very limited and it is not an area we know too much about. We do feel that historically Carers organisations are branded towards older Carers and that this is something that needs to be addressed to meet the needs of younger adult Carers. Dementia generally tends to be linked to older people."***
> Tanya Stephens, North West Kent Carer Support Service – written evidence

3.2.3 The select committee has not been able to identify any dedicated public sector provision in the KCC area for people with younger onset dementia, apart from a small residential unit in Edenbridge, however details of a project for people with Younger Onset Dementia in Medway are given on page 36. Evidence has been received of voluntary sector provision that has been put in place to meet the needs of people with younger onset dementia locally but provision is not even across the county. Some local voluntary sector provision is listed on the next page.

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[27] Reinhard Guss, Consultant Clinical Psychologist, Mental Health Services for Older People, Clinical Lead for YOD, KMPT - Presentation at Consultation event 11th April

- Dover District & Thanet Carers' Support run a fortnightly Activities Project which includes carers (gardening, cooking and eating lunch together)
- East Kent Independent Dementia Support (EKIDS) run dedicated groups
- The Alzheimer's Society in Maidstone run monthly informal gatherings (with a separate facilitated group for carers)
- The Alzheimer's Society at Park Lodge, Tudely (near Tonbridge) run two dedicated sessions per week

> ***"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 . . ."***
> Janet Britt, EKIDS – written evidence

> ***"Young-onset dementia is a growing problem – some provision of dedicated services in Kent should be planned, both for day and residential care. Those involved should look at what St Mary's provides and achieves, which, while it is not perfect, is still far in advance of anything available in Kent."***
> Sally Parsonage, Carer – written evidence
> Details of services provided at St Mary's can be found at:
> http://www.olddeanery.com/stmarys/young-onset-dementia/

3.2.4 People with learning disabilities can now expect to live longer but as noted previously, those who live into their 50s and 60s, while still 'younger people' in terms of dementia are at much greater risk of developing it than the general population. Partly due to the use of Direct Payments to purchase services there may be a lack of data on where people with learning disabilities are living in Kent. It is therefore difficult to plan interventions and services for people with a learning disability who may develop a dementia in the future.

GOOD PRACTICE AND INNOVATION

Medway Horticultural Project for people with Younger Onset Dementia

A horticultural project was set up in Chatham for people with younger onset dementia in the Medway area. People can be referred to the scheme by their Admiral Nurse, Community Dementia Team or doctors at the Memory Clinic. The project was established on a broad evidence base including the therapeutic benefits of access to natural spaces; the opportunity to nurture and to take part in productive social activities and the benefits of sensory stimulation linked to reminiscence. Underpinning the project are the principles and indicators of wellbeing in dementia outlined by Tom Kitwood (1997):

Assertion of desire or will
Acceptance of other people with dementia
Ability to experience and express a range of emotions
Initiation of social contact
Affectional warmth
Showing evident pleasure
Self-respect
Social sensitivity
Humour
Creativity and self-expression
Relaxation
Helpfulness

The group's facilities include 2 large gardens with greenhouses, shed and fishpond. There are outside areas with tables and chairs and those dedicated to specific projects e.g. topiary and growing in cold frames as well as an indoor area and kitchen.

The group meets once a week and an atmosphere of mutual respect is fostered, with everyone working together. Though the project is garden based there are opportunities for socialising, music; crafts; with lunch at every session and regular outings, with venues chosen by participants, which have included an organic garden, country parks, local museum, river boat trip and visits to the coast. There is a Christmas pub lunch every year. Some participants also meet monthly to work on another garden at Medway Hospital.

The primary objective is to promote social inclusion. Peer support is a natural feature of the project which specifically aims to help maintain skills and promote the gaining of new skills through meaningful activities that are relevant to the age and ability of the participants (and which are not catered for by mainstream services). Participants' give feedback on every session and staff/volunteers keep progress records on every person as well as discussing the group as a whole.

The Project is staffed by volunteers and a team of experienced professionals which at different times could include psychologists, occupational therapists, Community Mental Health Nurses and Admiral Nurses working co-operatively with a group co-ordinator and voluntary services co-ordinator. Volunteers are often psychology students wishing to gain experience in dementia care.

Sources: Frances Cook, Community Support Worker, KMPT – written evidence
Kitwood, T (1997)
Reinhard Guss, Consultant Clinical Psychologist, Mental Health Services for Older People, Clinical Lead for YOD, KMPT - written evidence

3.3 GPs and dementia

3.3.1 Community Health support for people with dementia and their families is provided by:

- GPs and surgeries
- Community Mental Health Teams for Older People
- Memory Services (clinics)
- Admiral Nurses who specialise in dementia care
- Home Treatment Service (Dementia) Teams in East Kent

There are 129 GP practices in Kent; 115 in West Kent and 104 in Eastern and Coastal Kent. 90% of people who have health concerns will in the first instance contact their GP but many people in the early stages of dementia try to cover up the problems they are having and it is friends and relatives who are most likely to raise concerns. Therefore the experience of individuals and families who approach their GP for help is a crucial step in the journey towards determining what is wrong; making sense of what has been happening and accessing help and support. A good GP-patient-carer relationship can greatly improve the experience of diagnosis and living with dementia.

> ***“Our GP was very helpful in linking us with the Dementia Care team, but also one of the few professionals who maintained support for us, and especially to me, through a devastating period and in the aftermath.”***
> Sally Parsonage, Carer – written evidence

3.3.2 Family doctors have a pivotal role to play if early diagnosis of dementia is to be achieved for more people living with the condition. In 1999/2000 the “Forget Me Not” report[28] said that 50% of GPs did not feel that they had been adequately trained to be able to diagnose Dementia, and by the time a subsequent report was written, this percentage had increased further.[29]

3.3.3 A study of GP attitudes in Kent was carried out in 1997 by the University of Kent’s Tizard Centre and another study was carried out by the Audit Commission in 2001, enabling changes in attitude over a four year period to

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[28] Audit Commission (2000)

[29] Ian Bainbridge - Deputy Director for Social Care & Local Partnerships, Department of Health South East (Deputy Regional Director of Transforming Adult Social Care Programme Board) – Hearing 9th March 2011

be monitored. Comparison of Kent data revealed that attitudes were changing significantly for the better; particularly where GPs had confidence in support services and good ‘back-up’ from specialist psychiatric colleagues. Those GPs committed to early diagnosis were aware of its importance to facilitate treatment, and the opportunity to plan for the future.[30]

3.3.4 Currently, GPs who suspect dementia in a patient can perform a number of tests including memory tests and blood tests; designed to flag up problems. It is important for GPs to eliminate other conditions and illnesses, such as deafness, depression and delirium, before referring people on to Memory Services for more detailed assessment and diagnosis. The main process of assessment and diagnosis happens in a secondary care setting often at some distance from where people live. The relevant NICE Dementia Quality Standard (2) says that: *People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.*

GOOD PRACTICE AND INNOVATION

DEMENTIA SCREEN – BLOOD TESTS

Following collaborative work between GPs and specialists from Medway Memory Clinics an audit by KMPT demonstrated that procedural changes could speed up blood test requests and ensure that results reached the correct Memory Clinic. This work is now being taken forward in East Kent where GP time could be saved if all individual blood tests required prior to referral are denoted as a ‘dementia screen’.

Dr Ciao Bettini – written evidence
Reinhard Guss - written evidence

3.3.5 The two charts that follow (Figures 6 and 7) show the number of people who in 2008 were on GP registers in Kent as having a diagnosis of dementia, shown alongside the number of people believed to have dementia now and in the future based on national data. The charts show very clearly how few of the people living with dementia in Kent have so far received a diagnosis. Registers of people diagnosed with dementia are kept by GP practices participating in the ‘Quality Outcomes Framework’ which is explained further on page 40. The rate of diagnosis varies considerably across Kent (between GP practices) as well as across the UK as a whole. In diagnosis ‘league tables’ for the UK, West Kent PCT is ranked 128th and East Kent PCT is ranked 140th out of 169 PCTs.

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[30] Milne, A., Hamilton-West, K., and Hatzidimitriadou, E (2005)

Figure 6: The number of people on GP dementia registers in West Kent PCT area (104 practices)[31]

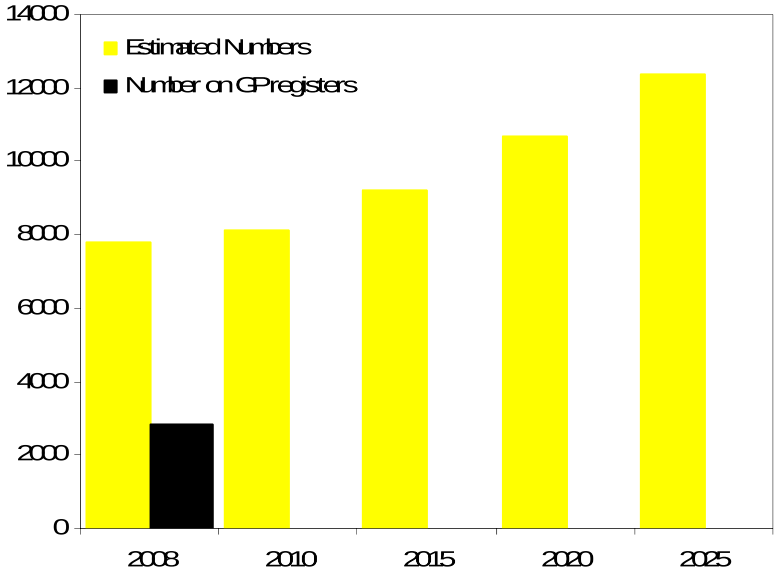
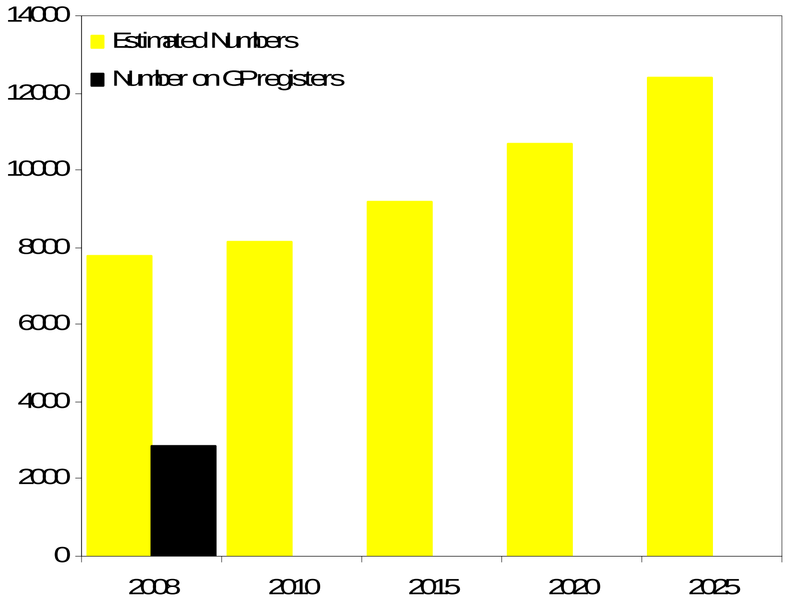


Figure 7: The number of people on GP dementia registers in Eastern and Coastal Kent area (115 practices)



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[31] Adam Cook, Specialist Information Analyst – written evidence (Source: Public Health Observatory – Dementia Primary Care Dashboard - 2008 data)

Quality Outcomes Framework

The Quality Outcomes Framework (QOF) was introduced in 2004 as part of the General Medical Services Contract. GP practices can obtain additional payments as a reward for good practice by recording a range of information about the particular illnesses and conditions included in the framework. In 2009/10 over 8,000 GP practices participated in the voluntary scheme, representing 99.7% of all registered patients.

Whitstable Medical Practice, in Eastern and Coastal Kent, for example, has achieved the maximum reward payments by developing good practice in all the aspects required to be reported under the Quality Outcomes Framework.

Dementia is only one of 20 clinical aspects on which GPs are requested to gather data (others, for example, are asthma, diabetes and heart failure). 'Points' (upon which payments are based) are awarded to GP practices in relation to the registration and review of dementia cases. The current dementia 'indicators' are:

- DEM 1: The practice can produce a register of patients diagnosed with dementia.
- DEM 2. The percentage of patients diagnosed with dementia whose care has been reviewed in the previous 15 months

Payments are made to practices in relation to their QOF results but, for example, these are not as significant for dementia as they are for other conditions such as diabetes. GP practices in East Kent in 2009-10 achieved 77.8% of their potential scores and in West Kent 82.2% in relation to Dem 1 and Dem 2.

The accurate recording of dementia prevalence by GP practices is of key importance so that service planners know where and for how many people services and support might be needed in the future and to facilitate workforce planning.

For 2011/12 reporting under the QOF, the National Institute for Health and Clinical Excellence (NICE) has introduced another indicator: 'to identify people with a treatable cause of dementia'.

Data Source: NHS Information Centre for Health and Social Care

3.4 Memory Assessment Services (specialist Memory Clinics)

3.4.1 Memory services of one kind of another have been around for some time primarily to provide a diagnosis and treatment service for people with memory problems. However, one of the key objectives of the National Dementia Strategy was to establish a national network of memory services or ‘clinics’. In addition to assessment, diagnosis and treatment, it was intended that clinics would provide information, care and support. In the Department of Health consultation document on the NDS[32] it was estimated that the cost of these services would be more than offset by a 10% reduction in costs to the public purse from admissions to care homes.

3.4.2 In Kent, Memory Services are commissioned by the Kent Primary Care Trusts (PCTs) from the Kent & Medway NHS and Social Care Partnership Trust (KMPT) who developed a Memory Assessment Model in response to the National Dementia Strategy. The services were developed with no extra investment by reconfiguring existing services. The view has been expressed to Members that this has been at the expense of services for older people with functional mental health problems. (Functional mental illnesses are those such as depression or neurosis where physical performance is impaired but there is no evidence of dementia.) Older people are particularly prone to depression which can accompany dementia and their needs in this regard may not be met. It is also important that professionals can distinguish between dementia, depression and delirium (from infection).

3.4.3 The principles of the Memory Assessment Service are to:

- provide an access/referral point for adults with a suspected dementia
- improve detection of patients with dementia in the locality
- improve referral rates of patients with dementia to ensure a diagnosis and access to other services
- encourage detection and referral of patients earlier in their illness
- provide an all-age service (engaging younger people with dementia)
- provide consultation for people with a Learning Disability (LD) with a suspected dementia by developing joint partnerships/assessments with LD services
- ensure an appropriate level of referrals from BME communities [33]

No particular evidence was received about the proactive elements of the service such as improving detection of patients or encouraging early diagnosis. People access a Memory Clinic by being referred to the

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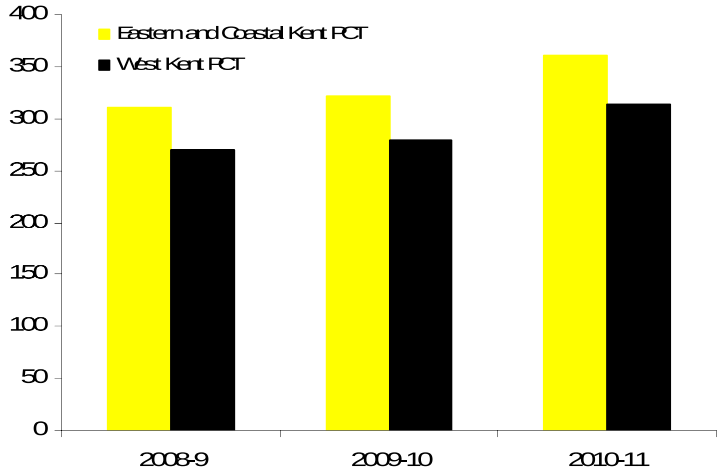
[32] Department of Health (2008)

[33] Kent & Medway NHS and Social Care Partnership Trust (n.d.)

Community Mental Health Teams for Older People. The Service is also designed to provide pre and post diagnostic counselling as well as post-diagnostic group sessions. Most referrals are made by GPs but on occasion social care professionals or voluntary sector workers refer people about whom they have concerns. Despite being allied to Older People's Services it is also the point of referral for people with younger onset dementias.

3.4.4 The full results of a national survey to determine how well the memory assessment network has been established across the country are expected later in 2011. Provisional results on the Service commissioned by the Kent Primary Care Trusts show that £1,565,000 was spent in East Kent (6 clinics) and £923,000 in West Kent (4 clinics) in each of the financial years 2008-9, 2009-10 and 2010-11[34]. The clinics have seen an increasing number of people each year as shown in Figure 8 below.

Figure 8: The number of people assisted by the Kent Memory Assessment clinics



3.4.5 The ten Memory Clinics in the KCC area plus one in Medway, take place in Ashford, Canterbury, Dartford, Dover, Maidstone, Sevenoaks, Shepway, Swale, Margate and Tunbridge Wells (shown on the map on page 53). There is no clinic in Gravesham or Tonbridge and Malling, these being served by Dartford and Sevenoaks/Maidstone. Six East Kent districts also benefit from Home Treatment Service Teams which provide an enhanced dementia care service for up to three months post-diagnosis. The Select Committee was told that Home Treatment Services are commissioned in East Kent but not in West Kent[35] and Members believe this too contributes to the imbalance of services that exists for people with dementia across the county.

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[34] NHS Information Centre for Health and Social Care (2011)

[35] Justine Leonard, Service Line Director for Older Adults and Specialist Services, Kent and Medway NHS and Social Care Partnership Trust – Hearing 8th April 2011

A Medical or a Social Model of dementia?

The debate about a medical or clinical model of dementia versus a social model has been around for many years. The clinical model of dementia defines it in terms of its symptoms; the social model focuses on positive aspects and quality of life issues, recognising:

- That dementia is not the fault of the individual
- That we should focus on skills and capacities retained, not those lost
- That we can understand people with dementia - history, likes, dislikes (if we make the effort)
- That people with dementia need a supportive environment
- The value of appropriate communication
- The value of opportunities for rehabilitation or re-enablement
- The responsibility to reach out to people with dementia lies with people who do not (yet) have dementia.

Both models are factual but evidence from people with dementia and carers to this review indicates that they would benefit from a greater focus on the social impact of dementia and from an integrated care pathway which provides continuous social support, with medical interventions as necessary. Looking at dementia in purely clinical terms has seemed to perpetuate the view that there is ‘no hope’ and led to people with dementia being considered as somehow less deserving of care than other people. Adopting a more socially-focused model ensures that people have better, more joined up support from the time of diagnosis or identification of needs in relation to dementia. Guidance provided by NICE and SCIE in 2006 sought to progress this issue and the guidance was revised in March this year to take account of new prescribing protocols which allow people access to treatment earlier on.

NICE (2007) and Gilliard et al (2005)
Dr Robert Stewart, Medical Director Kent and Medway PCT Cluster – written evidence

3.5 Diagnosis in primary care?

> ***"Why does a consultant have to give the diagnosis – why isn't the GP diagnosis good enough? Why does there have to be a crisis before you get help?"***
> Belinda Merritt, Carer – Hearing 9th March 2011

3.5.1 As noted, most people visit their GP for preliminary screening and tests before being referred to a Memory Clinic. People with more complex needs may first be assessed at home by a Community Psychiatric Nurse or attend an outpatient clinic where they can be seen by a doctor. However, the Select Committee heard that communication within specialist services can be a problem and that gaps in support have developed after diagnosis because of a lack of cohesion between Memory Clinics and GPs.

> ***"At times it appeared that even members of the same team did not communicate with each other, especially in the NHS group. At one critical point all the key people in that team (e.g. Consultant, Care Coordinator and Admiral Nurse) were on holiday, seemingly with no cover, which meant there was absolutely no support for us at a critical time! And the Care Coordinator admitted to not being able to speak with the consultant on an urgent matter – a link which would seem to be fairly important!"***
> Sally Parsonage, Carer – written evidence

People expressed a range of views about their GPs and their experience with specialist memory services. Some GPs were praised as being very supportive; others were said to have had very little knowledge of dementia or the services available to support people. In general, what people said they valued was a good relationship with the professionals involved in their care, regardless of where they were based. For several people, however, transport to services (including post diagnostic groups) was a problem and this can lead to non-attendance.

> ***"It's a long bus ride and even if we go by taxi, getting someone with dementia ready for an appointment early in the morning is very difficult."***
> Carer – Consultation event

> ***“When they had to travel to Canterbury, the no-show rate was 40%, now it is down to just 5%.”***
> Dr John Ribchester – Hearing 23rd March 2011

A number of other issues were identified in relation to difficulties people had in obtaining a diagnosis. In some cases this was due to the person having a rarer form of dementia (which understandably takes longer to identify). More often, concerns were in relation to the ability and willingness of professionals from different sectors (or the same organisation) to work together. People with dementia and carers also told the Select Committee about problems they had in accessing crucial information and support post-diagnosis.

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> ***“None of the services are not doing their job but what they are not doing is doing it together.”***
> Carer – Consultation event

> ***“There is no medication to address the vascular dementia and no monitoring.”***
> Carer – Consultation event

3.5.2 The Select Committee believe there are multiple benefits to be gained by the provision of more dementia assessment/diagnostic services being provided within or closer to primary care settings (GP practices), though as has been noted this may not be in line with current NICE guidance. The benefits could include reduced waiting times, lower rates of non-attendance for appointments and improved triaging of cases (determining those which could benefit most rapidly from specialist intervention and those whose needs might be better met by other forms of support.[36]). This has not so far been tested in East Kent although the Whitstable Medical Practice Integrated Social and Healthcare Project (WISH) has demonstrated how integrated care can meet many of these objectives. The Early Intervention Project in North West Kent has also been shown to connect people with support earlier on. Further details of both Projects follow.

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[36] Dr David Kanagasooriam – written evidence

GOOD PRACTICE AND INNOVATION

Whitstable Integrated Social and Healthcare Project (WISH)
Whitstable Medical Practice

The WISH model of integrated service delivery developed by Whitstable Medical Practice (WMP) is unique in Kent. Its design will provide better outcomes for people including those with dementia at less cost to the NHS. WMP has 19 GPs and 100+ staff serving 33,000 people, 92% of those in the catchment area, of whom 209 people are diagnosed with dementia.

WISH is about the redesign of healthcare provision. It has 5 workstreams, including ‘Long Term Conditions’ focused on Respiratory Illness Cardiology, Diabetes, and Dementia. It aims to improve the patient experience by providing care closer to home with shorter waits. An outpatient clinic has been developed to address current problems with dementia care including:

- **Delayed diagnosis**
- **Remoteness of Day Care**
- **Inadequate and disconnected provision**
- **Concerns about care in hospitals**
- **Lack of carer support and information**
- **Inappropriate drug therapy**

Future developments will include a CT Scanner and ‘one stop shop’ for outpatient services. Key to its success has been investment in Estuary View Medical Centre, an innovative new building for general practice and integrated healthcare.

Tea
For
Two

And time for you

A friendly and supportive café for people with dementia and their carers
In partnership with volunteers from Friends of Whitstable Hospital and Healthcare

1st and 3rd Friday of the month
2pm – 4pm

Whitstable Health Centre,
Harbour Street, Whitstable, CT5 1BZ

25th March, 15th April, 6th and 20th May, 3rd and 17th June

For more information, please call Kate Sergeant on
01732 370330 or 07584503747

Registered charity no. 296645

Working with partners Dementia UK (Admiral Nurses), Alzheimer’s Society, Friends of Whitstable Hospital & Healthcare and a Patient User Group the project has developed with and for patients. It involves integrated chronic disease management; urgent care; elective and diagnostic services and enhanced rehabilitation at Whitstable and Tankerton Hospital. WMP has strong research links with Edinburgh and Canterbury Universities. It is a national NHS Commissioning Exemplar Site and an Advanced Training Practice. Major savings to the NHS have resulted from the new outpatient’s clinic and reducing the use of anti-psychotic drugs.

GOOD PRACTICE AND INNOVATION

Early Intervention Project – ADSS, North West Kent

The Project was implemented in North West Kent by Alzheimer’s and Dementia Support Services (ADSS) who found from earlier work with the BME community and from speaking to carers and people with memory problems with whom they work, that there could be long delays in people seeking help from their GPs. With funding of £223,000 from the Big Lottery Fund, they concentrated on working with GPs in their area to encourage people with memory problems to come forward earlier on.

Having gained approval from the Primary Care Trust (PCT) and Practice-based Commissioning Group (PBC), a leaflet was produced and targeted at patients aged 65-75. They also worked with specialist colleagues at the Memory Clinic to produce a template for the assessment of people with memory problems by GPs and practice nurses. There is clear evidence from the project that people with a dementia are being picked up, and linked into support, earlier on in the course of their condition. The five year Project began in 2008 and has gradually gained momentum, with sixteen North West Kent GP practices currently involved.

A most valuable outcome of the project has been its ability to address the social as well as clinical needs of patients and carers; who are sent an information pack and the ‘Who Cares?’ booklet. An ADSS client liaison officer then visits patients at home within the next three weeks to assess individual/family needs. People do not need to be diagnosed in order to receive support and are assisted based on their needs which may for example be met by day care, support at home or befriending.

“Sometimes it is Vascular Dementia and is there really any need for a firm diagnosis at age 90?” (Dr Viniti Seabrooke, Project Manager)

The only problems identified with the format have been administrative, e.g. with some practices finding it difficult to allocate the time to offer patients 20 minute appointments for the initial assessment of memory problems.

The success of the project has resulted in ADSS beating more than 400 other UK charities to win one of ten national IMPACT Awards. The Project has been submitted to the Department of Health and is acknowledged as good practice by its inclusion in the Compendium of Good Practice across the South East.

Sources:
Visit to ADSS – 7th February 2011
Dr Viniti Seabrooke - Hearing 29th March 2011
National Skills Academy – Social Care (2011)
Health and Social Care Partnership South East (2011)

3.5.3 It has been emphasised to the Select Committee that for GPs the support and expertise of specialists in making a detailed diagnosis of dementia would be crucial. Assessment of dementia can often be a lengthy process, in some cases taking several months, though the average is around 8 weeks.[37] For some e.g. very elderly people presenting with signs of dementia the burden of rigorous testing and scans is one which has to be added to managing other health issues or disabilities. A familiar setting closer to home could also seem less threatening and present fewer problems such as those relating to access and transport.[38] The Equality Act 2010 makes it clear that people should not be discriminated against on the basis of age but the Select Committee feels that there could be a more personalised approach to the issues of diagnosis, care and support.

3.5.4 The Select Committee believe that GP practices have a vital role to play in ensuring continued care and support for people wherever their assessment and diagnosis may take place and that it is the lack of a shared care protocol in Kent which is impeding initial progress on this issue. In the future Members believe also that more people could be diagnosed in a primary care setting (with appropriate specialist support) closer to home and hope that NICE may take this into account when reviewing current guidance in this respect.

3.6 A Shared Care Prescribing Protocol

3.6.1 The Department of Health (DH) provide guidance on shared care for drug prescribing where sophisticated or complex treatments initiated in secondary care are then prescribed by a GP (such as in the case of dementia). An 'Effective Shared Care Agreement' (ESCA) is the current method by which this may be set in place to allow the GP for a person with dementia to take on prescribing responsibility. Anecdotally, a common barrier to putting such agreements in place is said to be reaching agreement on funding. Individual ESCAs which are required for each patient and a number of criteria must apply; for example, that the patient's condition is stable or 'reasonably predictable';[39] and also that 'any training required by GPs and their staff should be identified and provided to a satisfactory standard by the specialist department seeking the shared care arrangement.'

3.6.2 A study of 381 patients receiving dementia medication between 2006 and 2008 was carried out in the North East of England with the aim of arriving at a protocol for shared care prescribing. Key findings of the study were that:

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[37] Justine Leonard, Service Line Director for Older Adults and Specialist Services, Kent and Medway NHS and Social Care Partnership Trust – Hearing 8th April 2011

[38] Dr David Kanagasooriam – written evidence

[39] Department of Health (n.d.)

- 96% of requests to GPs were accepted
- hospital prescribing and dispensing rates fell dramatically
- patients benefited from closer relationships with their GPs
- GP involvement in dementia care was enhanced
- GPs had more timely and comprehensive out-patient communications
- Implementation of the scheme resulted in growth in drug[40] spend decreasing from 21% (2006/7) to 5% (2008/9) releasing considerable NHS resources[41]

3.6.3 According to the Kent Public Health Report 2010, prescriptions for dementia medication currently cost £2.2 million per year and changes to prescribing could mean this figure rises to £4 million per year. To give some idea of the savings which could result from Shared Care prescribing arrangements in Kent, if the projected increase of £1.8 million was reduced by 16% this would equate to savings of £288,000 (money which could be better spent on support for people early on in their diagnosis of dementia).

3.6.4 Shared care prescribing can also prevent patients being harmed by unintended interruption of treatment following admission to hospital (or other acute medical unit), a situation which has been specifically reported to the Select Committee. This could be one of the components that make entering hospital such a negative experience for people with dementia. If in addition to being in a strange environment people are denied medication which alleviates symptoms of dementia, this could trigger a negative cycle of events from which some people are unable to bounce back sufficiently to return home, and may as a result enter residential care in an unplanned manner.

> ***"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."***
> Carer – Hearing 9th March 2011

3.6.5 The Select Committee also believe that there is a need to encourage GPs to be proactive in inviting all patients receiving a diagnosis of dementia in secondary care (at a Memory Clinic), to attend a brief appointment at their GP

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[40] Cholinesterase Inhibitors (CHEI)

[41] Tim Donaldson, Trust Chief Pharmacist/Associate Director of Medicines Management, Northumberland Tyne and Wear NHS Foundation Trust – written evidence and personal communication

practice, regardless of medication status, so that they experience seamless treatment at this difficult time. A review/interview could potentially be carried out by another appropriate health professional at the practice and would be of most benefit if it included a chosen relative/carer/supporter. In this respect the Select Committee believes that the Quality Outcomes Framework measure of a review within 15 months is far too late.

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.

3.6.6 Another important aspect which concerns Members is that people with dementia who live in residential care homes may not receive regular visits (or any visits) from their GPs.[42] Regular monitoring is particularly important for patients who are on anti-psychotic medication.

GOOD PRACTICE AND INNOVATION

Virtual GP Practice – Salford Care Homes

In Salford, Greater Manchester, a ‘virtual GP practice’ has been in operation for two years. It was set up to meet the primary care needs of the most vulnerable people in residential and nursing homes as well as in respite, neuro-rehab, transitional and intermediate care beds; focusing on:

- Dementia and mental health care
- Palliative care
- Nutrition
- Medicines Management/Poly-Pharmacy
- Chronic disease management

The multi-disciplinary team includes 3 GPs, Care Workers, 2 Advanced Nurse Practitioners, Dietician, Physiotherapist, Practice Nurse, Active Case Manager, Occupational therapist, Pharmacist, Dementia Specialist Nurse, Practice Manager, Administrative staff and an End of life care facilitator. Together the team has been able to address health inequalities and bring a more consistent approach to prescribing and delivery of primary care to people in residential care while reducing inappropriate admissions to hospital and improving end of life care.
Source: Vyas, H (n.d.)

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[42] Deborah Connolly, Consultant Psychiatrist for Older People, East Kent - Hearing 8th April 2011

3.7 Voluntary Sector Support Services for people with dementia

3.7.1 The network of support for people with dementia and their carers offered by third sector[43] organisations in Kent comprises both national and local organisations; including those who are geared towards dementia-specific support such as:

- Dementia UK
- the Alzheimer's Society,
- Alzheimer's and Dementia Support Services
- East Kent Independent Dementia Support

There are also organisations geared towards providing services and support for older people such as Age UK (which resulted from a merger between charities Age Concern and Help the Aged) who in addition offer some dementia-specific services. Organisations such as Crossroads Care, which exist primarily to support carers, include among their clients carers for people living with dementia. For many of these organisations there is a considerable overlap in roles; and those that provide support primarily for carers may also support the person they care for. Admiral Nurses, for example, are part of Dementia UK but employed by the Kent & Medway NHS and Social Care Partnership Trust. They work primarily for carers, but also support the cared for person. (Appendix 8 shows where Kent Admiral Nurses are based.)

3.7.2 Figure 9 on the next page gives an indication of the range of services and support for people with dementia provided by voluntary sector organisations in Kent.

3.7.3 A map showing the location of services offered by ADSS, the Alzheimer's Society and EKIDS is given on page 53. Some of these services have been running for several years; others are relatively new. Also included are the locations of Memory Clinics and Admiral Nurse bases (in some cases these are at the same site). A darker shaded background on the map shows the areas where more people with dementia are estimated to be living (based on hospital admission data).

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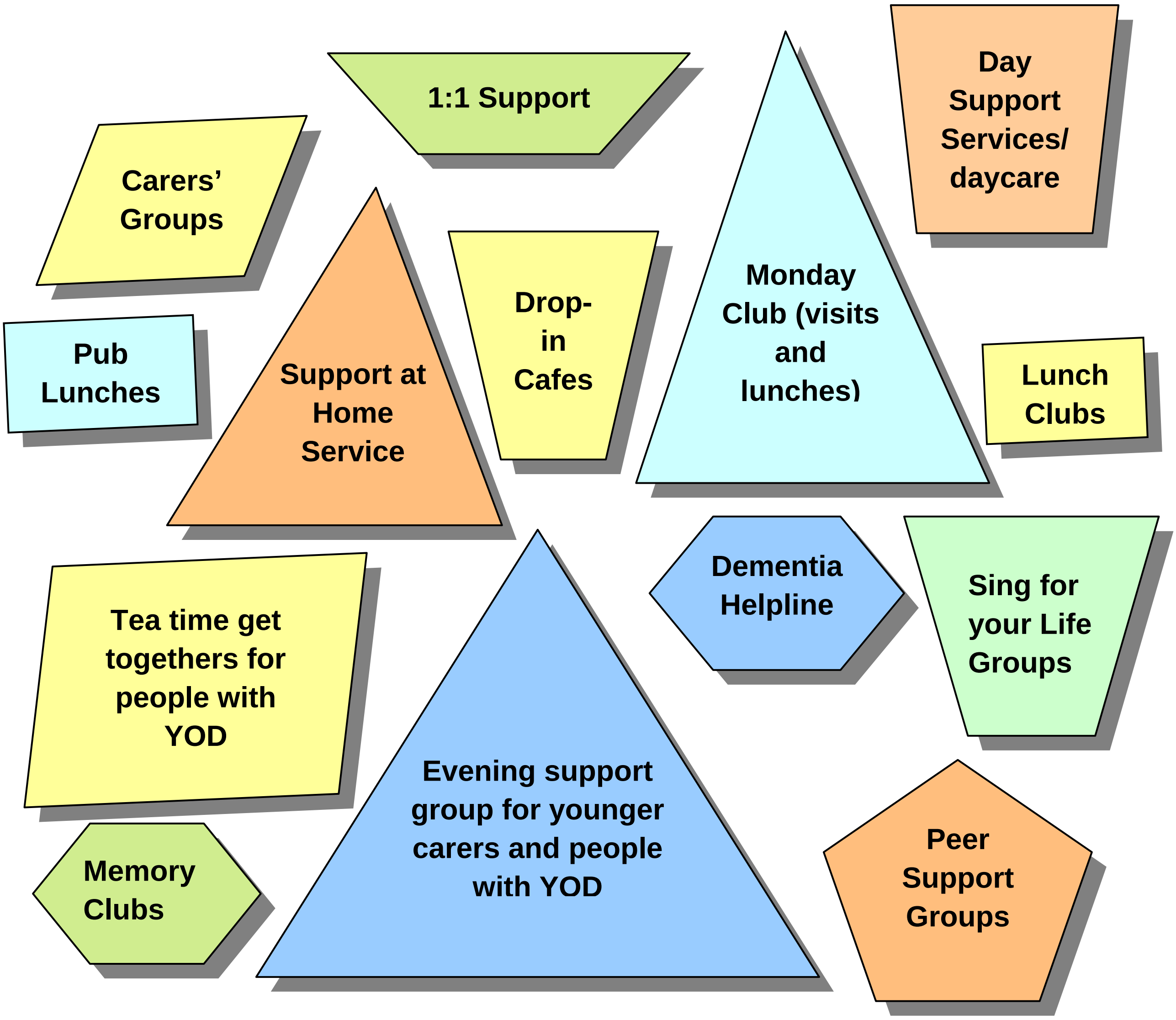
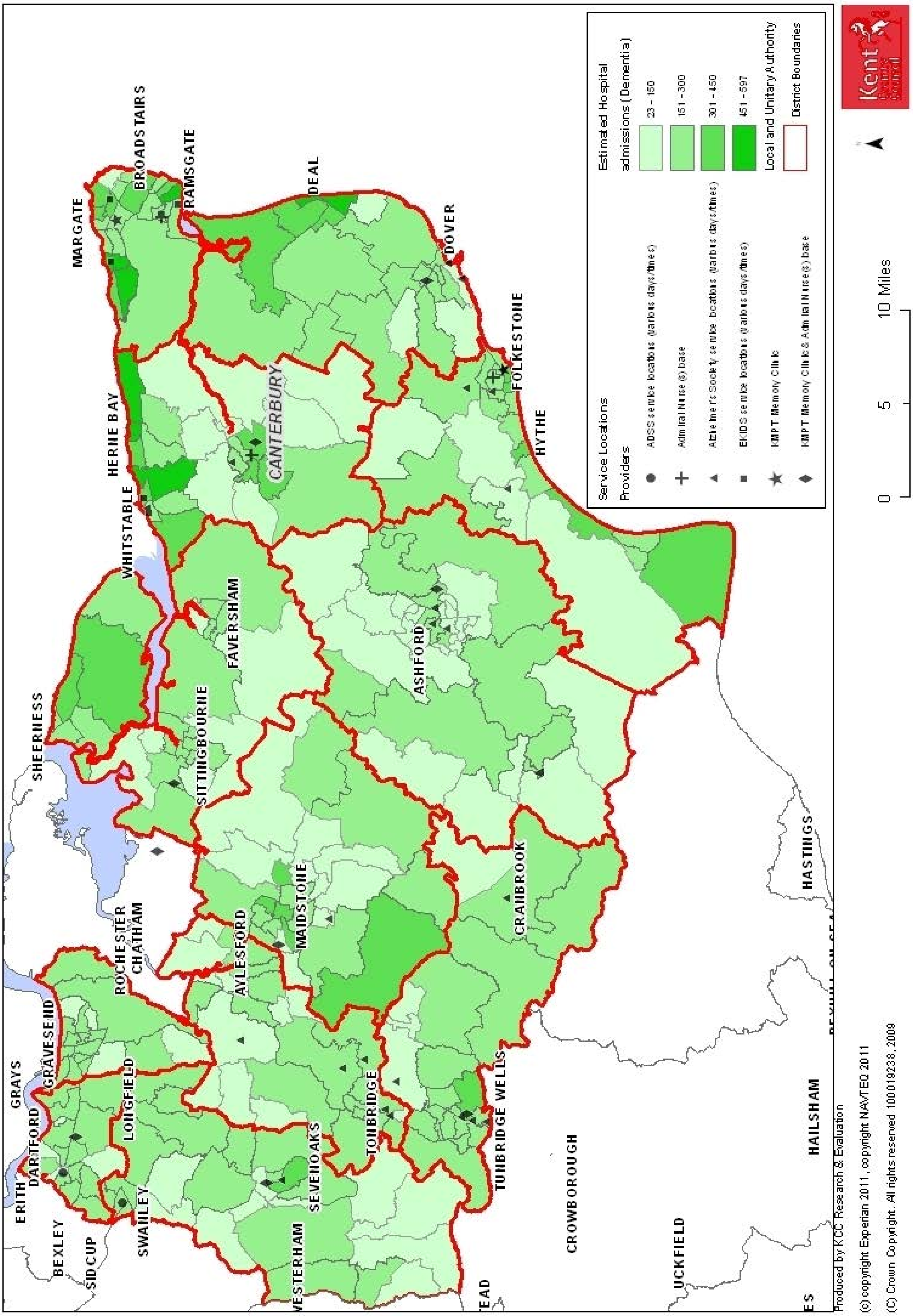
[43] Charities, voluntary sector, social enterprises – not for profit organisations

Figure 9: Varied services and support provided by voluntary sector organisations in different parts of Kent



3.7.4 Voluntary sector dementia support organisations in Kent are becoming more aware of the whole range of services available and there is generally a spirit of co-operation, despite the fact that as providers they are competing for the available funding. While it is to the advantage of Kent residents that a variety of support services exists, its availability is not consistent. There is a patchwork of service provision in the voluntary sector as well as in the health and social care sectors and Members believe service commissioners have a vital role to play in ensuring the development of a more evenly distributed range of services across the county, from which people can choose what meets their needs and what interests them as individuals.

Figure 10: Map showing the location of Memory Clinics, Admiral Nurses and Voluntary Sector Support Groups



Produced by KCC Research & Evaluation

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3.7.5 Third sector organisations are funded in a variety of ways but funding cuts to local authorities are nevertheless affecting all sectors and evidence from the voluntary sector to this review revealed considerable anxiety about the future. Members were struck by the way voluntary sector representatives continue to provide a consistent level of support to people with dementia and carers in a time of financial uncertainty.

3.7.6 In 'Bold Steps for Kent', KCC commits to developing a new approach to Community Asset Transfer in relation to the management of its buildings and facilities by community groups, the voluntary sector and social enterprises to enable a new model for the delivery of public services. Members believe that voluntary sector dementia care providers and local communities could benefit from reductions in in-house provision by KCC in terms of respite and day care provision through proactive consideration of the cost-effectiveness of asset transfer.

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.

3.8 Admiral Nurses

3.8.1 Admiral Nurses, named after 'Admiral Joe' Levy, are specialist dementia mental health nurses who work to improve the quality of life of families living with dementia, helping them to remain positive and develop the skills they need. They are supported by the Charity Dementia UK which, along with partners in Health and Social Care, is involved in promoting and developing the role, for example through regular Practice Development Days.

3.8.2 Nationally there are only 75 Admiral Nurses and the role is often compared to that of Macmillan Nurses, 3549 of whom work with cancer patients and their families.[44] It should be noted, however, that while Macmillan Nurses offer hands-on care, this is not the role of Admiral Nurses.

3.8.3 Since the original 2 Admiral Nurse posts were introduced in West Kent in 1999, the Service in that part of the county gradually expanded to 6 posts and in 2009 a further 4 were added, this time to work closely with GPs on a Primary Care Project to improve access to services. In 2008 6 posts were created in East Kent bringing the total for Kent and Medway to 16 out of a national total of 75 making it the largest team in the country.

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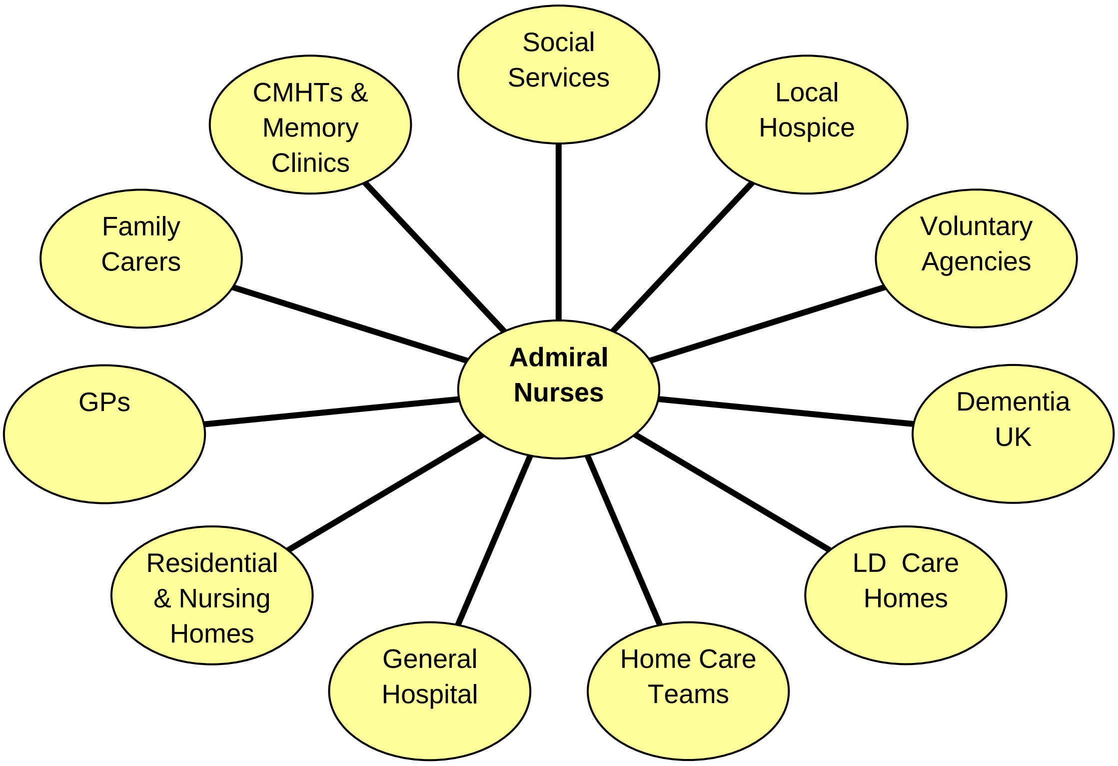
[44] At June 2011 – online at: http://m.macmillan.org.uk/article/name/howwecanhelp-nurses-aboutmacmillannurses

> ***‘There is one Admiral Nurse for every 1,312 people with dementia in Kent.’***

3.8.4 In Kent, Admiral Nurses are employed by KMPT in partnership with Dementia UK and their work is integrated with the Community Mental Health Teams for Older People (CMHTOPs). Figure 11 below shows how Admiral Nurses can provide a vital link for people with dementia and their carers to the other agencies and individuals providing care.

Figure 11: Partnership working of Admiral Nurses:[45]



3.8.5 Training for Admiral Nurses (AN), which is funded by Dementia UK, is very specialised, with candidates needing to be Registered Mental Nurse (RMN degree) qualified (some are also Registered Nurse RN qualified) and with good experience before taking the required specialist courses. The knowledge and experience brought to the role is highly valued by people with dementia and carers in Kent and all evidence to this review is extremely positive with the only criticism being about people’s ability to access the service.

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[45] Pat Brown and Fiona Martin, AN Clinical Leads for East & West Kent – Hearing 23rd March 2011

3.8.6 Evidence from America as well as experience in West Kent shows that a good model for working could be to have AN as case-coordinators in GP surgeries or as consultants to other professionals. Currently, with only 16 AN in the county resources are stretched and people referred to the service may have a long wait or never receive AN support. A strength of the role is that intensive support can be provided when needed but in depth knowledge of families enables Admiral Nurses to 'navigate' care and provide case co-ordination. Some of the projects Kent AN are involved with are shown below.

GOOD PRACTICE AND INNOVATION

. Activities and joint work of Admiral Nurse in Kent & Medway

- Family Carer Clinics -Tenterden, Dover, Deal, Thanet, Sittingbourne, Maidstone
- Admiral Nurse run Clinics (held at 4 Age Concern Day Centres in East Kent)
- Post diagnostic services - Ashford, Sittingbourne, Folkestone, Margate, Dover
- Daytime carers education programmes - Canterbury/Coastal, Dover/Deal, Maidstone, Dartford, Gravesham & Swanley, Medway.
- Support for the Continuing Care and Admission Wards at the Frank Lloyd Unit, Sittingbourne and the Winslow Ward, Ashford.
- Evening carers education - 4 week course in Maidstone.
- Mentoring/joint work with Dementia Support Worker, Crossroads Care Thanet.
- Initial support for the Dover Sing for your Life and the Silver Song Club project
- Joint work and training with local hospices in Kent on a dementia pathway.
- Joint facilitation with the Alzheimer's Society in Dover/Deal, Folkestone, Tonbridge, Tunbridge Wells and Maidstone of carer support groups.
- Couples Reminiscence Groups for Shepway, Dover and Ashford.
- Joint work with the Sunlight Centre and Age Concern in Medway
- GP surgery-based support group in Medway
- Maidstone pilot scheme developing a Resource and Information pack for Residential and Nursing Homes (also working jointly with East Kent)
- Maidstone pilot scheme supporting care home staff in supervision and training
- Pilot scheme for people with learning difficulties in care homes

Source: Jacqui Wharrad, Dementia Pioneer, Dementia UK

3.8.7 Members believe that the capacity of the Admiral Nursing service needs to increase in order for it to respond to the growing numbers of people affected by dementia. To enable a wider service and full use of AN skills the consultancy role of the AN needs to be developed further. Senior AN should expand their role to manage a team that includes AN in development roles (and possibly Practice Specialist Nurses who have undergone dementia training and/or dementia nurses from Community Mental Health Teams[46]) who could take on teaching and educative roles in the community with people with dementia and their families; across health and social care services and the independent and voluntary sector, supported by strong links to higher Education (e.g. the Dementia Services Development Centre at Canterbury Christ Church University.) The framework that is in place (currently funded by Dementia UK) for monthly supervision and practice development is valued and essential for these roles to develop.

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.

3.9 Home Care (Domiciliary) Services

3.9.1 Domiciliary services are those provided to people in their homes. People referred to Social Services will have their needs assessed and following a ‘Community Care Assessment’ the package of help put in place might involve washing and dressing in the morning, getting ready for bed in the evening and other aspects of care such as supervising medication or preparing meals though the Select Committee have learned that there is an unequal application of eligibility criteria with regard to some elements of care.[47]

> ***“When personal care had been assessed as being required, it was easier to also arrange for shopping help and medication checks, but this was often dependent on the specific care manager dealing with a case.”***
> Dr Sam Roberts, Clinical Psychologist – written evidence gathered from Home Treatment Service/Older People’s Psychological Services CMHTOP

Home care is commissioned mainly from private providers and the Select Committee is only aware of specialist dementia domiciliary care being available in Dover though this situation may change as voluntary sector organisations (two known so far in West Kent) obtain CQC registration and are able to provide home care. People’s ability to contribute to the cost of their care is determined by financial assessment, carried out by a Finance & Benefits Officer.[48] KCC in-house domiciliary care services have been rebranded as Kent Enablement at Home, primarily to provide short term (up to

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[46] Dr David Kanagasooriam – written evidence

[47] Dr Sam Roberts, Clinical Psychologist – written evidence gathered from Home Treatment Service/Older People’s Psychological Services CMHTOP

[48] Kent County Council (2011)

6 weeks at a time) help for people upon leaving hospital. Longer term home care support is only available in a few places where pockets of service remain, for historical reasons e.g. a dementia service which still exists in Maidstone[49]. A major cause of concern from evidence provided to this review is the inability of current services to fully safeguard people with dementia living at home – two specific incidents were reported to the Select Committee:

> ***"A person with dementia possibly at stage 5 (mid stage) was given inappropriate care. He was asked to live alone yet when he tried to cook he caused a fire by using a bottle of oil to cook chips. Neighbours had to rescue him; he further went missing so police had to search for him. Despite all this a care package was not implemented so the pathway is not working."***
> GP – personal communication

> ***"Mum was asking for lunch at 10.30a.m. I told her it wasn't lunchtime but when I left, Mum put a microwave meal in for the time it would take in a normal oven – she went into another room and meanwhile the dish caught fire and the flat filled with smoke. When the care agency carer turned up at 12.30 she turned it off. Another thing mum has done is tried to cook a cucumber till it exploded."***
> Belinda Merritt, Carer – Personal Communication

3.9.2 Around 8,000 people in Kent receive home care and though, as noted above, it is means tested 30-40% of clients are on a basic income and do not pay for the home-based support they receive. Only people with savings or investments over £23,250 would receive no help with their care costs.

3.9.3 Services commissioned or provided by KCC are 'generic' and not set up with a focus on dementia. Evidence to the Select Committee indicates that a specialist dementia care manager role did exist briefly in the past. It was based in a multi-disciplinary, hospital-based team with Health colleagues. The role has, however, become generic and now focuses on enablement.[50] So, while Social Services were integrated with KMPT (Mental Health service providers) between 2002 and 2007, they are no longer integrated with respect to dementia.

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[49] Richard Munn, Assessment and Enablement Manager – written evidence

[50] Sandie Crouch, Assessment and Enablement Worker – Hearing 5th April 2011

“*on the front line there is a slight disconnect between us and our partners*”.
Richard Munn, Assessment & Enablement Manager – Hearing 5th April

One of the changes to the service which was a source of great frustration to many of the people to whom Members spoke while visiting memory cafes and during consultation events was the lack of continuity in Adult Social Services since the changes made to care management. A single point of contact i.e. having a named social worker or care manager was felt by many to be key to accessing information and resources.

“Now, if you seek help you may get to speak to someone through the call centre, but then the case is closed and another one started. If you call again another time, even if it is a recurrence of the same issue, a new ‘case’ is opened.”
Carers - visit to St Christopher’s Memory Club, 8th March

3.9.4 KCC does not currently record whether people who are receiving domiciliary support have a diagnosis of dementia or undiagnosed memory problems. It is therefore not possible to quantify the proportion of domiciliary care provided that is specific to dementia. Anecdotally, a high proportion of referrals relate to people who have some form of diagnosed or undiagnosed memory problems. Members believe that problems, including those exemplified in 3.9.1, are more likely to arise where care workers providing support have neither the ability to recognise that a person has dementia, nor sufficient understanding of the condition. They may therefore be unable to judge the impact and likely results of requiring a person to perform, unattended, tasks which they may find confusing or difficult.

3.9.5 Though there are providers who specialise in dementia care, the majority of care is provided by mainstream domiciliary care agencies. KCC ‘expects a certain level of training in dementia awareness’. However, there is no stipulation in contracts regarding training, in the absence of a quality standard. New dementia commissioning guidelines issued by the Department of Health provide contract inserts in order to clarify those aspects of knowledge and training which are required in order to provide care for people living with dementia. The issue of training is considered further in section 7.

3.9.6 One carer who provided evidence to the review indicated that her mother's domiciliary care support had so far involved more than 12 different care workers coming into her mother's home (not all of whom she had had the chance to meet) which was very distressing for her mother and had led on several occasions to carers being refused admission or asked to leave. Other evidence suggests that that care workers may take such 'refusals' at face value and not be sufficiently well-trained to consider the role dementia may play in this.[51]

3.9.7 Continuity of support is of prime importance to people with dementia. This is so that there is more chance for the person being supported to become familiar with the person coming in. Furthermore, with greater continuity, a worker can become familiar with what is 'usual' for the person they are assisting and thus flag up any changes or indeed recognise what may be initial signs of a dementia developing. People with dementia should not be subjected to changes to their domiciliary care routine unless these have been clearly communicated to them beforehand in the most appropriate way possible (which might for example mean using communication methods to take account of sensory disability, particular forms of address or translators if appropriate). This aspect is one of the key measures of dignified service provision for all older people and one to which people with dementia are equally entitled.[52]

> ***"I don't blame the carers, but they are given so little time and there is no continuity for the client and somebody who suffers from dementia needs that familiar face each day because of the nature of the illness."***
> Carer – written evidence

> ***"For the first 3 years he was still able to live by himself with only minimal extra help from the family such as bringing him meals and doing his laundry. Then it became obvious he needed more assistance in his home by way of help from a care agency. Unfortunately there was no continuity of care as different carers were being sent in and they didn't get to know D and understand his needs."***
> Carer – written evidence

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[51] Dr Sam Roberts, Clinical Psychologist – written evidence from Home Treatment Service/Older People's Psychological Services CMHTOP

[52] Centre for Public Scrutiny (2010)

"Domiciliary care workers not being on time, not adapting to individual needs (the system they have to work under not being suitable for people with dementia)."
Consultation event 15th April - in answer to question 'what needs improving'?

3.9.8 The current 'set up' of home care services was identified as a problem rather than workers themselves who it was often felt were trying to do their best in quite difficult circumstances. Carers for people with dementia told Members that workers are inadequately trained (or untrained) in dementia, are task oriented and bound by rigid time–slots, none of which is conducive to person-centred dementia care. People would most value a system which recognised the need to work *with* the person with dementia rather than *do things to them*. Some of the most valued workers are those who take time to interact with a person with dementia. Ironically, those with a more flexible approach might not be meeting the more 'task oriented' requirements of their role even though they are treating the person with dementia with the dignity and respect they deserve and enabling them to do as much as possible for themselves.

"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."
Barbara Hagan, Manager, Maidstone & Malling Carers Project

3.9.9 The need for more consistent support for people in their own homes was an issue identified by many people giving evidence to the Select Committee and one which has been highlighted by other consultations and research.

"Lack of continuity and training in domiciliary care caused me to put M in a nursing home – it was for my sake, not his."
Presentation (online): Barbara Pointon
MBE Think Relationships, A Carer's View

3.9.10 KCC maintains a list of approved domiciliary care providers in Kent who have achieved a rating of Good or Excellent with the CQC. As noted previously, the Select Committee learned that during the course of the review, voluntary sector dementia support organisations in West Kent have now achieved the required registration with the Care Quality Commission (CQC) and are thus now able to provide specialist home care support.

3.9.11 Research comparing the relative costs and benefits of generic and specialist domiciliary care for people with dementia was commissioned by the Department of Health in 2010[53]. Looking across a range of local authority types, the research had the following key findings:

- The definition of specialist domiciliary care varies – some ‘generic’ services focused on dementia e.g. through training; elsewhere the availability of 24hour care denoted specialist provision.

- Half the local authorities commissioned some form of specialist care for people with dementia but the proportion of the care provided that was non-generic was small.

- There are few specialist providers and only 9% of domiciliary care hours for people with dementia are commissioned from them.

Furthermore the research found that quality measures of specialist provision related to providers being able to assess the ability/needs of the person with dementia as well as being involved in reviews. Personalised care e.g. use of life story work or care that was culturally specific, was rare. In relation to the comparative costs of care, while the average costs of specialist care were £3 per hour higher there was overlap (and some generic care was more expensive). The overriding conclusion was that good practice and ‘appropriateness of care’ outweighed the significance of care being ‘generic’ or ‘specialist’. Part of the research involved ranking the importance to people of various aspects of care and from figure 12 on the next page it can be seen that the feature valued most highly was continuity of care followed closely by the home worker having been trained in dementia care. It is significant that those two aspects were valued even more highly than respite.

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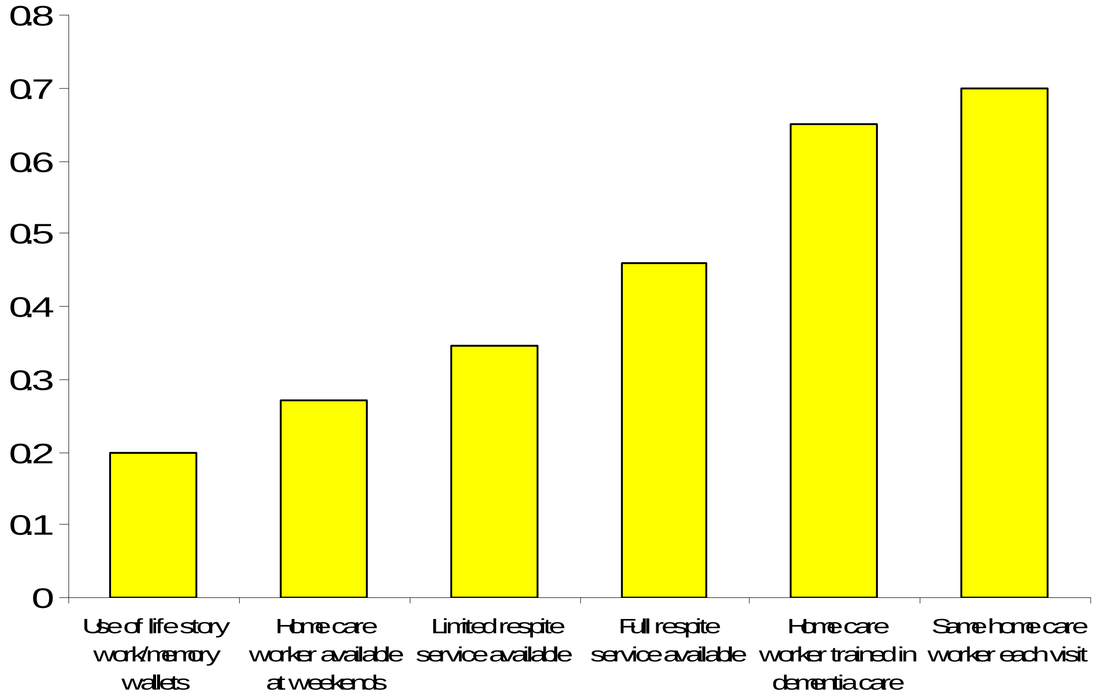
[53] Challis, D. et al (2010)

Figure 12: Chart showing findings of PSSRU research into the relative values attributed to different aspects of domiciliary care



3.9.12 The Department of Health's new dementia commissioning guidance envisages that commissioners can ensure that 'generic' home care services meet the specific needs of people with dementia through the addition of new requirements in contracts and provides 'contract inserts' outlining the dementia-specific needs which the provider must be capable of meeting. A recommendation about training for KCC enablement workers is made in Section 7.

3.10 Residential Care Services

3.10.1 Residential care services were the topic of an in depth Select Committee Review which took place in 2001 and which had a particular focus on dementia[54].

3.10.2 'Living well with dementia in care homes' is the third strand of focus of the coalition government's revised implementation plan for the National Dementia Strategy.

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[54] Kent County Council (2011)

3.10.3 According to the Audit Commission's report 'Don't Stop me Now', only 3% of people over 65, 18% of people over 80 and 28% of people over 90 live in residential care. However, residential care remains an important option for many people and more residential places are likely to be required in the future.

3.10.4 Only a small proportion of people with dementia who are living in residential care are in specialist places, yet around 75% of older people in non-specialist residential care have some form of dementia[55]. It is important to families that place a relative in residential care that care that meets their loved-one's needs can be found locally (whether or not this is in a specialist dementia or EMI placement) so that important contact can be maintained. The review learned from one carer in his 90s that it had been invaluable that once his own health failed, and his wife, for whom he managed care for several years, was placed near to his home so that despite his own disability and ill-health he could make the daily journey (on foot) to be with her. Evidence from a national database of Citizen's Advice Bureaux enquiries showed that (in another local authority area) the husband of an 84 year old woman with Parkinson's had been placed in a care home in a neighbouring county as there were none that met his needs closer to home. This effectively meant she was placed in immediate financial distress as she wished to visit three times a week but there was no available public transport and taxis would cost £150 per week. It is crucial that people are able to access good quality care close to where they live to maintain the beneficial contact and support of their closest family.

3.10.5 In relation to people living with dementia the Select Committee have heard how disruptive and damaging unplanned admissions at times of crisis can be to both carers and the person with dementia; it is preferable for discussions to take place early on to reduce the burden of guilt that many carers carry and to ensure that the preferences and expectations of the cared for person can form a central part of plans for future care.

3.10.6 Adhering to the wishes of the person with dementia as far as possible (where they are/have been communicated or made clear) is paramount but for carers' own wellbeing the 'message' that entry to a care home is a failure or betrayal is not helpful and can stand in the way of good relationships between families and care home staff and the provision of the best support to people in residential care.

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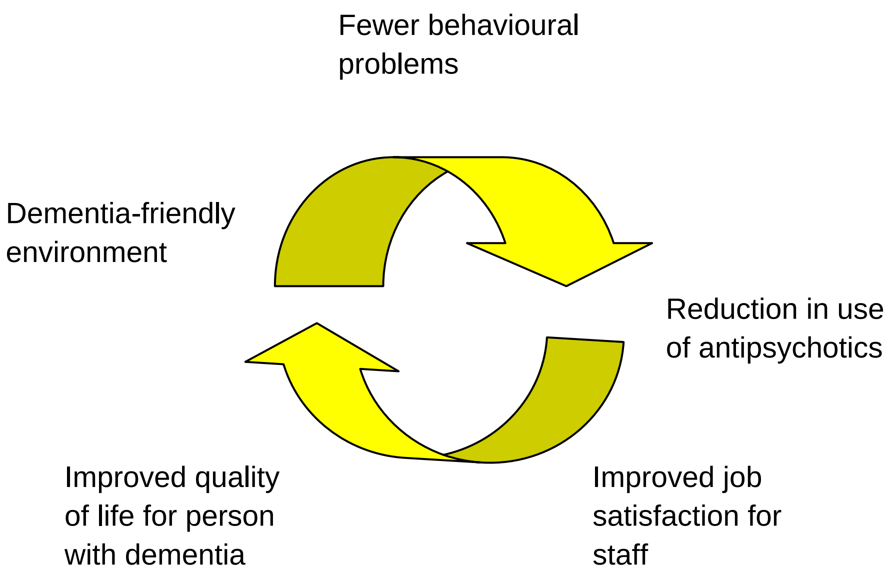
[55] Macdonald, A. J. D. et al (2002)

> ***“Perpetuating this view is detrimental to the welfare of caring families and undermines engagement with families following admission of their partner or parent”***
> Dr Graham Stokes, Director of Dementia Care, Bupa Care Homes – Presentation 7th June, Ashford

3.10.7 As we are gaining insights about dementia and can focus more on the perspective of people living with the condition, a body of evidence about design features and how they can improve the lives of people with dementia is building. Members were able to visit residential settings that have incorporated many of these design features which can impact positively on residents’ wellbeing and quality of life as well as reducing the need for antipsychotic medication to address behavioural problems, creating a virtuous circle of improvement. A number of case studies follow which demonstrate one or more of these aspects.



GOOD PRACTICE AND INNOVATION

FEATURES OF GOOD DESIGN FOR PEOPLE WITH DEMENTIA

- Muted colours and low contrasts – no dark bands on carpets which could look like holes or thresholds
- Symbols, graphics and text to identify rooms/areas e.g. pictures of food to identify dining room
- Personalised doorways to bedrooms to aid orientation e.g. with picture frames, memory boxes, individual colours, numbers with personal meaning
- Outdoor space – safe and secure to aid free movement with familiar objects to stimulate memories
- Raised lighting levels with good balance of natural/artificial light
- No long narrow corridors
- No bedroom doors opposite one another
- Bathroom mirrors that can be removed or covered in case they cause distress
- Glass-fronted doors on cupboards, cookers and fridges so things can be found easily

The Design Council is currently running a competition to get people thinking about how design can help improve the lives of people with dementia, with a monetary prize to help put ideas into production.

Sources:
Dementia Services Development Centre (University of Sterling) (n.d.)
Jane Barnes, Head of Provision Modernisation – Training Session 26th January 2011
Online at: http://www.designcouncil.org.uk/dementia - entries by 1st September 2011

GOOD PRACTICE AND INNOVATION

PRIORY MEWS – REDUCTION IN USE OF ANTIPSYCHOTICS

Antipsychotics are given to people with dementia to help manage difficult behavioural symptoms e.g. shouting, agitation and problems with sleeping. Potentially dangerous side effects can compromise patient safety and benefit only outweighs risk for some people with severe symptoms. Priory Mews care home in Dartford has a specialist dementia care unit for people aged 65+ (average age 85/86). It has experienced nursing staff and facilities have been adapted to improve both long term care and respite, with reduced use of antipsychotics:

Staff training: There are 211 full/part-time and bank staff plus volunteers. Some recruits are qualified; others chosen for their skills and empathy. In addition to basic training in dementia; Safeguarding of Vulnerable Adults and Managing Challenging Behaviour, staff complete 'Person First' training which involves residents' families. 'Person First' is also available to nursing students and at Darent Valley Hospital, some staff convert to the 'dementia' setting. There is also a therapeutic approach to nursing in the home and care staff interact socially with residents when undertaking personal care. Staff attend courses based at Bexley College for Palliative Care and Dementia Care dealing with things such as family needs and financial support and a college tutor also visits the home. Older members of staff are doing NVQs and Business Management training and Senior Carers also undertake training known as 'Train the Trainer' which helps them to cascade their knowledge effectively.

Physical environment – free movement: The colour and design of walls and flooring have been muted to assist people with sensory impairment. Staff are proactive in what they do; for example evidencing that the colour change had a positive effect (and in fact went against BUPA colours), winning an award for their efforts. The lounge/dining area has brightly coloured picture signs to help people find their way around. Artwork (pictures of bright flowers and film stars) is also popular and people are helped to recognise their own room by having a favourite famous person's picture on the door and a memory box on the wall outside. There is safe outdoor space and doors are left open in the summer. Gardens have patio furniture and also chickens and rabbits. Four residents who were carpenters enjoy helping the gardener with outdoor jobs such as varnishing chairs. Other residents help with tree planting and fruit picking. To help with sundowning, lounge lights are left on; there are snacks available and clubs for people who have no awareness of it being night. Residents' relatives have on occasion questioned why someone can walk into their relative's room but it has been explained that it is not possible to lock doors, and people will be steered away rather than excluded. (Contd…)

(Source: Visit to Priory Mews – 10th February 2011)

Self expression and socialising through individual therapeutic and purposeful activities: Each house has an activity co-ordinator who arranges evening art, music and drama activities. There is a 1950s reminiscence room as well as computer stations and a sensory room. Residents also use the Wi and have inter-house tennis! Men as well as women have protective tendencies and doll therapy has been shown to work well with both sexes, enabling people to cuddle and nurture.

Person centred care planning: Two senior sisters are dementia champions and use behaviour mapping to see what triggers any challenging behaviour. One resident was distressed and her behaviour became challenging every time her daughter left after a visit. The daughter said that she would sit reading her paper during visits as her mum was unresponsive. Following a discussion, she interacted more with her mum e.g. massaging her hand and talking to her about what was in the paper. Soon she was assured by a squeeze of the hand that her mum was benefitting. Both were as a result happier and the challenging behaviour stopped.

Involvement of friends and relatives in care: Each house has a sister and charge nurse and is open to families at any time. A dementia steering group involves residents' families and there are quarterly residents meetings and an annual meeting with the site manager. People stay afterwards to chat and find mutual support. Instead of bland corridors, dementia units have comfortable 'stations' with memorabilia where families gather or sit to read magazines and have tea.

Effective local healthcare links: Staff have recently started to make 'passports' for residents with essential information to help if there are any spells in hospital. There are a number of step-down beds, funded by Health. in an arrangement with Darent Hospital. A consultant and a doctor come in once each week and there are meetings with the local hospital every month. A joint pilot project with KMPT showed that that some GPs were too quick to prescribe antipsychotic drugs (which were found to be less effective after 6 weeks) and not looking at alternatives. Learning from the review will be shared with GPs who will be given a contact number and assisted with advice that can be given to people.

Involvement in local community: The home is part of the community. Very young children up to those at secondary school come in to sing for residents. Age Concern visit for afternoon tea and there is a Community Tea Week each summer. Outside entertainers e.g. Irish Dancers visit the residential dementia unit every 6 weeks. A car-washing day raises funds, and residents enjoy helping out. A family 'car park party' was organised for the Royal Wedding featuring lots of red, white and blue. Residents chose the entertainment which ranged from Pearly Kings and Queens to an opera singer. All community interaction helps to raise awareness of dementia and show there is nothing to be scared of.

GOOD PRACTICE AND INNOVATION

CIRCLE DANCING FOR PEOPLE WITH DEMENTIA

Circle Dancing has its roots in traditional folk dances from around the world. Taking part brings positive feelings from being in a group and has been shown to enhance physical and emotional wellbeing.

Kath Kershaw and Cynthia Heymanson have been training people to lead circle dancing groups since 2008 and since then have either commissioned or directly led more than 56 workshops, training 710 staff.

People with dementia can participate in dances both seated and standing according to their ability, Dances or movements are often 'performed' holding onto a 'stretchy band' which can be made from a variety of materials, linking everyone together. The use of music from around the world ensures there is something for everyone and actions like holding hands, touching, swaying, other movements as well as reminiscence help to stimulate and engage people.

"I thought I had lost everyone,

and suddenly I had all these people again."

Care homes, day centres, community groups and assessment & rehabilitation wards have all used the technique and found that:

- Circle dance can be enjoyed by people with or without dementia who may have physical disabilities (including wheelchair users), learning disabilities or sensory disabilities
- Family members and staff also benefit from taking part
- Circle dance can be used weekly or more frequently to benefit staff and residents; evening sessions have been found to be particularly beneficial and relaxing
- Sessions can invoke memories and feelings of caring, inclusion and wellbeing even in people who were shy or reluctant to join in.

'One resident and his wife were well-known local dance teachers,

it was the first time they had danced together for years.'

Source: Cynthia Heymanson – written evidence
www.circledanceindementia.com

4 SUPPORTING EARLY DIAGNOSIS BY RAISING AWARENESS AND REDUCING STIGMA

4.1 Stigma associated with dementia

> ***"Mum does not think she has dementia. She won't have any talk about it and is a very proud person."***
> Belinda Merritt, Carer – Personal Communication

> ***"Image is everything. Minority Groups need to be confident that when they raise issues they will be heard."***
> Roger Newman MBE, joint founder of EKIDS and former carer – Hearing 29th March 2011

4.1.1 Sometimes people are aware that they themselves or a loved-one have a problem perhaps with memory or some other aspect that could relate to a dementia, but are unable, or choose not, to seek help because of the associated stigma.[56]

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[56] The cover shown was produced for Dementia Awareness Week in July 2011 (reproduced here with kind permission from the Alzheimer's Society)

4.1.2 The language used by professionals and organisations can sometimes contribute to stigma. For example, the Select Committee learned about a Council Tax leaflet which features in prominent writing on the front the wording ‘reductions for people who are severely mentally impaired’. A voluntary sector support worker spoke of the need for greater sensitivity when working with people with dementia and carers. In trying to assist clients with form-filling, she had had to hide the negatively worded leaflet from them to avoid causing upset and offence.[57] By considering the potential impact of communications, situations like this could easily be avoided.

4.1.3 A better understanding is also needed of the way that people in Kent from different cultural backgrounds might receive health messages generally and about dementia in particular. People can feel excluded from services because of their ethnic origin or sexuality if the images and language used lead them to believe that services are not ‘for them’, so the use of inclusive images and language to communicate about dementia support and services is vital.

> ***‘There also remains within society a real problem of stigma and fear associated with dementia which can delay early diagnosis and the accessing of good quality care. As a result of the associated stigma, people with dementia may feel devalued and excluded from mainstream society.’***
> KCC (2010)

4.1.4 The Kent Annual Public Health Report on dementia acknowledges the negative effect of stigma; however, it is heartening to note that many people who spoke to the Select Committee feel that things are steadily improving.

4.1.5 It may be that the strength and quality of family and social networks play an important part in people’s experience of stigma. The Select Committee has heard with sadness about situations where people’s social circles have fallen away; visits have become infrequent and the person with dementia and carer are effectively excluded from their ‘normal’ social circle and activities. But Members have also heard about situations where friends and social or religious groups have come together and rallied round, providing great support. One gentleman whose wife now lives in a care home spoke of the way in which their Church community had formed a ‘list’ of volunteers to visit her and a rota so that she could receive Holy Communion while in the care home, as she had always received in Church before. There is a broad

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[57] Judy Ayris, Dementia Outreach Service, Age UK Canterbury - personal communication

spectrum of experience and while some people have philosophically adopted the view that ‘you get to know who your real friends are’, awareness-raising that can allay peoples’ fears and reduce the number of people who feel they have to struggle on alone could reap considerable rewards.

4.1.6 Deeply held beliefs can also influence the likelihood of people responding to health messages, however inclusive they may seem. Some Asian and African cultures for example, do not recognise the concept of dementia and have no specific word for it. Cultural beliefs and misunderstandings can therefore prevent people from accessing services and impact on whether early diagnosis is achieved. Perhaps more importantly, it is essential that professionals (including commissioners) focus on these issues to ensure they do not inadvertently make things worse for people living with dementia and their carers in communities where there are taboos around mental capacity.

4.1.7 The Select Committee also learned that it is detrimental when some professionals assume that people from Asian communities may not have sought support for a loved one with dementia since extended family have ‘rallied round’ and contributed to care. Aside from any issues of taboo, they are just as likely to be dispersed geographically and to have work responsibilities to maintain. The Select Committee learned that people from BME communities living with dementia and their carers can become very isolated as a result of this kind of assumption. A study in West Kent among South Asian carers, found many were looking after family members with advanced dementia without seeking any formal support.[58]

4.1.8 Evidence provided to the Select Committee indicates that reaching into communities through community groups and community leaders is an effective method of engagement. Furthermore, the Equality Act 2010 places a clear duty on public bodies to ensure that their commissioning takes account of these issues and there is a good evidence base within Kent to show that placing dementia-related services (such as peer support, memory cafes or dementia advisors) within community settings familiar to and used by particular communities will be important to ensure that no groups of people are disadvantaged (or disenfranchised) by the way services are set up.

4.1.9 A holistic approach to raising public awareness about dementia would be one which explained about the avoidable risks (obesity, smoking, high blood pressure and so on); informed about the likelihood of it affecting more people in the future and emphasised the fact that diagnosing dementia early gives you time to get appropriate treatment, plan and make decisions so you can get on and enjoy life. Raising public awareness should also contribute to

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[58] Seabrook, V & Milne, A (2004)

'building compassion' in all communities for people who have dementia and those who care for them. The Early Intervention Project outlined on page 47 shows how successful this type of approach can be in communities where people may have previously been worried about coming forward with their concerns.

4.1.10 KCC's Social Innovation Lab Kent (SILK) will in the future be looking at social marketing as a way of reducing the stigma associated with dementia and further reference to their work is made in the final section of this report. (Social Marketing is a way of communicating messages of important public concern for the benefit of the 'recipients' of the message and wider society, rather than the organisation 'doing the marketing', as in commercial situations.)

4.1.11 A government media campaign in 2010, which aimed to dispel some of the fears people hold about dementia, had the strap line, "I have dementia – I also have a life," and this was followed up in the Spring of 2011 with further media campaigns in the North West and Yorkshire, using different media including TV, radio and print in an effort to get family members or friends to persuade loved ones with memory problems to seek help from their GP. The pilot schemes cost £1.2 million. The TV advert can be found on YouTube.[59]

4.2 Knowing when to seek help

"We are at the tipping point of public awareness".
Ian Bainbridge, Deputy Director for Social Care & Local Partnerships, DH South East – Hearing 16th March 2011

"The most important <thing> is to get early diagnosis - when I went to my GP she immediately referred me to the specialist at the Dementia Unit at my local hospital where I was assessed, had brain scans, diagnosed and started treatment which amazingly has taken away most of the symptoms of dementia (although I do have side effects). Without the treatment I was struggling to look after myself at home. I have also been going to the Alzheimer's Support Drop In monthly for 15 years or more, since my husband was diagnosed and after he died 6 years ago. I continued to go, to support other carers etc and I now have it myself! This has helped so much."
All Party Parliamentary Group on Dementia (2011)

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[59] Department of Health (2011)

4.2.1 The Select Committee has heard that in some cases the view is still held (even among some GPs) that memory problems are necessarily part of the normal aging process and this is not the case. In America the Alzheimer's Association has produced a list showing '10 Signs of Alzheimer's' (see Appendix 9). The 10 Signs explain clearly the difference between signs of concern and normal signs of ageing. As can be seen from the list referred to, this is largely a matter of degree but there is a need for the general public as well as professionals to have a better understanding of where the dividing line lies.

4.3 Raising public awareness of the modifiable risks

4.3.1 Prevention is a key theme of emerging health policy and a better-informed public can make important lifestyle decisions that could impact positively on their own health as individuals and on the prevalence of some illnesses and conditions and thus the ability of service commissioners and providers to ensure that health and social care needs can be met in the future.

4.3.2 Most diseases leading to dementia have unknown causes but there is consensus that regular mental and physical activity, a healthy diet and not smoking help to reduce the risk of vascular dementia and Alzheimer's disease; the two most common causes of dementia. According to the Alzheimer's Society addressing modifiable risk factors (such as those shown on the next page) could have a significant effect since 'delaying the onset of dementia by 5 years would reduce deaths directly attributable to dementia by 30,000 a year'.[60]

- Keeping active - Activities for older people (mental and physical)
- Eating a balanced diet
- Addressing other health needs such as obesity, blood pressure, dental health
- Giving up smoking – one study of over 5000 people showed smoking increased the risk of dementia by 100%[61][62]
- Reduced use of the 'chemical cosh' antipsychotic drugs[63]

4.3.3 The Map of Medicine guide to the clinical assessment of dementia contains a more comprehensive list of risk factors which are noted in full below:

- mild cognitive impairment
- Down's syndrome and other learning disorders

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[60] Alzheimer's Society, cited by Jacqui Wharrad, Dementia Pioneer, Dementia UK – written evidence

[61] NHS Choices (2011)

[62] Rusanen, M et al (2011)

[63] Antipsychotics more than triple stroke risk in dementia

- history of psychiatric problems
- lack of exercise
- limited social network

Risk factors - Alzheimer's disease

- genetic predisposition
- older age
- female gender
- history of head trauma
- hypertension (high blood pressure)
- hypercholesterolaemia (high blood cholesterol)
- obesity
- diabetes mellitus
- atrial fibrillation (irregular, fast heartbeat)
- smoking
- alcohol
- history of depression

Risk factors - vascular dementia

- older age
- smoking
- diabetes
- hyperlipidaemia
- hypertension

4.4 Raising public awareness to encourage diagnosis

4.4.1 It is difficult to measure the success of public health campaigns in raising awareness about particular issues over the short term. However, messages stay in people's minds when they 'strike a chord'. An example is the F.A.S.T. campaign aimed at raising stroke awareness and informing people what to do in an emergency. That campaign depicts powerful images of stroke damage being done and how fast action can minimize the effects and improve the outcome. The F.A.S.T. campaign is familiar to people and also features on the side of ambulances for even greater visual impact and coverage.

Face – Has their face fallen on one side? Can they smile?

Arms – Can they raise both arms and keep them there?

Speech – Is their speech slurred?

Time to call 999 if you see any one of these signs

4.4.2 Early diagnosis of dementia is not as acutely urgent as the need to respond to a stroke emergency but a similar approach could be used in Kent to encourage people to see their GP. The Kent Public Health Report 2010 indicates that one reason for low diagnosis rates may be failure to pick up around 55% of dementia cases at the ‘mild’ stage where symptoms may have so far gone unreported.

4.4.3 People in Kent could be encouraged to seek help early on by the use of a ‘catchy’ but informative message (the one given in the recommendation is intended as an example only) using different media such as email ‘sign offs’ or relevant websites in order to reinforce the message over a period of time.

4.5 NHS Health Checks

4.5.1 Members have been concerned from the beginning of this review that there is no consistent method across the county to aid the identification of early stage dementias. Vascular Dementia represents around 25% of all dementias and is a form of dementia for which the risk factors are relatively well understood, being largely the same as for stroke and heart disease, e.g. high blood pressure, high cholesterol, smoking and other modifiable risk factors such as a low level of physical activity, poor diet and being overweight. It follows that modification of behaviour could impact on the likelihood of an individual experiencing cognitive impairment as a result of vascular disease and on future prevalence of this form of dementia.

4.5.2 A programme of GP-based NHS Health Checks is currently being implemented nationally. It aims, over a 5 year rolling programme, to screen all 40 to 74 year olds[64] to assess their risk of developing diabetes, heart disease, kidney disease and stroke and offer advice on how to reduce their risk or manage their condition. There is discretion over what is included in the Health Checks and currently GPs in Kent are invited to participate in offering what is referred to as a ‘Local Enhanced Service’. However by 2013 the Health Checks programme will be a statutory requirement and while Medway has the highest percentage roll-out in the South East Coast NHS area, in the Eastern and Coastal Kent and West Kent PCT areas (KCC area) implementation has been slower. Stumbling blocks have been staff having the required competency to conduct particular checks, and agreements on funding. NHS South East Coast has now set challenging targets to boost take up of the scheme and those GPs not meeting the challenge and setting up a programme will be required to commission alternative provision.

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[64] (not currently on vascular disease registers)

4.5.3 It has been agreed that in 2011/12 11,195 checks are to be delivered in East Kent and 10,322 are to be delivered in West Kent. Data provided (at 6th June 2011) was incomplete for West Kent, but show that 521 Health Checks have taken place so far in East Kent.

- Baseline PCT funding is available for 90% of required checks to be carried out.
- The annual cost to each PCT of full implementation is around £1 million;
- GPs are currently paid £2 for identifying and inviting patients to attend and £23 for carrying out checks (which can be done by the GP, practice nurse or suitably qualified healthcare assistant).

4.5.4 Any business case to be made for the inclusion of dementia checks would therefore need to include details of the questions/tests to be added, how many minutes they would take and what the additional payment should be.

4.5.5 Evidence to the Select Committee indicates that the greatest benefit could be gained from the inclusion of ‘a brief set of standard questions about difficulties with concentration and memory which could help to pick up early stage dementias’.[65]

> ***Screening tools such as the Mini Mental State Examination (MMSE), Abbreviated Mental Test or GP-COG are effective in flagging up moderate stage dementias and Alzheimer’s Disease but … notoriously poor at detecting the visuospatial, executive functioning or praxis* difficulties and personality change that would develop early on in Vascular or Frontotemporal Dementias (which are more frequent at a younger age),”***
> Reinhard Guss, Consultant Clinical Psychologist, Mental Health Services for Older People, Clinical Lead for YOD, KMPT - written evidence
>
> *Praxis is the ability to plan and then carry out movement.

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[65] Reinhard Guss, Consultant Clinical Psychologist, Mental Health Services for Older People, Clinical Lead for YOD, KMPT - written evidence

4.5.6 Since the rates of diagnosis of dementia are low in Kent compared to elsewhere, the Select Committee considers that failing to include an appropriate ‘filter’ for dementias within this suite would constitute a missed opportunity to both to reveal early signs of vascular dementia as well as other types of dementia, including younger onset, and enable more people to be diagnosed early on and directed to support and help. Screening for the risk factors of dementia is recommended by NICE clinical guideline 42 (2006).

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:**

  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).**

4.6 Increasing young people’s understanding of dementia

4.6.1 Many children and young people already have, or will have experience of a relative with dementia and some parents may find it difficult to explain about the changes that they might see in a loved one. However, children are often open-minded, resilient and receptive to ideas about sensitive topics such as dementia if they are introduced to them in an age-appropriate way.

4.6.2 Figure 13 below shows books for young children, produced by Barchester for Dementia Awareness 2010 to help parents explain to children about dementia and allay fears about visiting relatives in care homes. The books were written by Virginia Ironside with input from children, people living with dementia, relatives, care home staff and a child psychologist. They are already being used by some schools, libraries, hospitals and GP practices.

Fig 13: Books for children produced for Dementia Awareness Week 2010[66]

4.6.3 Dementia UK’s community-based Admiral Nurses have been able to use the books to assist families and copies have also been circulated by the Alzheimer’s Society who have themselves produced a book for 7-11 year olds entitled “It’s me grandma, it’s me!”, shown overleaf.[67] There are relatively few books available to explain dementia to children of different ages, however the U.S. National Institute on Aging have produced useful lists of books for young children, for teenagers and for all children which can be found online.[68]

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[66] Reproduced with the kind permission of Barchester

[67] The booklet comes from an original story by Eileen Mitchell with illustrations by Melvyn Evans..

[68] U.S National Institute on Aging (2011)

4.6.4 Children's level of understanding will of course depend on their own age and ability but Members have been told how perceptive and caring young people of all ages can be towards people living with dementia. Young people with learning difficulties can also be particularly empathetic about 'the day to day challenges of living with a disability'.[69] The Alzheimer's Society provide useful guidance on talking to children of different ages about dementia and how to deal with the effects it might have on them.[70]

4.6.5 Many schools have close relationships with care homes in their communities and organise visits and activities which can be of great benefit to all concerned. During a visit to Priory Mews Care Home in Dartford, Members also learned of a young woman of 17 who wishes to become a nurse and organised work experience for herself with people with dementia, which has ultimately led to an apprenticeship. Volunteering and work experience co-ordinated by schools (or by individual young people) can clearly bring benefits in terms of enriching the experience of older people including those with dementia, and building a well-trained, knowledgeable and caring workforce for the future.

> ***"Most of the teenagers who hang round on the green have knocked on my door or phoned my daughter to tell us that her grandad is off again on a walkabout!"***
> Lorraine Hambidge, Carer – written evidence

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[69] Dr Penny Hibberd, Director, Dementia Services Development Centre, South East - Hearing 5th April 2011

[70] Alzheimer's Society (2010)

4.6.6 Children and young people could be made more aware about dementia as well as the opportunities to take part in volunteer work in their communities. The Select Committee believe it would be beneficial if a resource was made available to schools to promote discussion. Involving young people in production of the resource would also ensure that the information was communicated in a way which would be understood and appreciated by their peers.

4.6.7 It is also important that young people receive the Public Health messages about lifestyle that are targeted mainly at adults.

> ***"… people with early onset dementia have more issues with having to leave work, financial issues and children understanding what has happened to their parent… This needs to be highlighted to the young - all this binge drinking and poor diet could lead to dementia in early life. It is not only us older folks living longer… the youngsters are also at risk".***
>
> Former Carer – written evidence

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.**

5 SUPPORTING CARERS AND CARING RELATIONSHIPS

5.1 9 Steps for Carers of people living with dementia

5.1.1 The crucial role of carers for people living with dementia is acknowledged in only the fourth of the '9 steps' of 'Quality Outcomes'[71] which informed the Terms of Reference for this review: *'Those around me and looking after me are well supported,'* though it has been stressed to Members throughout this review that carers for people living with dementia make the journey alongside the people they care for at every step of the way.

5.1.2 In 2010, the Kent Carers Joint Needs Assessment recommended that services for carers who care for people living with dementia needed to be improved; highlighting that *'Carers need to be more involved in discussions about services for the person they care for'.*

5.1.3 Carers reported to the Select Committee that they are often excluded from discussions about their loved one's condition, care and support. A carer will often have a different view about the capacity of the person with dementia, who may think everything is fine, or be trying to pretend that it is. Voluntary Sector support workers also said that better support could be provided if some 'cultural' barriers between professionals, carers and voluntary sector supporters could be broken down. Professionals who take into consideration observations from a loved one are likely to have a more rounded view of circumstances. The Map of Medicine for dementia assessment directs that GPs should <u>consider</u> 'assessing reports from informants, e.g. carers, through interview' but 2006 guidance indicates that '*Health and social care staff <u>should take account of</u> the views of carers and relatives who describe behaviour that could be in keeping with dementia. This information, in conjunction with an assessment of the person concerned, will help with diagnosis and deciding on care.'*

5.1.4 Carers and former carers spoke highly of professionals, in particular GPs, who acknowledged their caring role by routinely including them in discussions. Ensuring that the views/observations of carers for people living with dementia are taken into account could also contribute to improved rates of diagnosis. Professionals are clearly, and rightly, concerned about patient confidentiality and the Select Committee appreciate the difficulties that GPs in particular must face.

5.1.5 Given the crucial role that carers play in supporting loved ones living with dementia a '9 steps for dementia carers' is proposed to complement the 9 steps for people living with dementia. A draft, which could provide a basis for discussion and consultation, is shown on the next page.

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[71] Department of Health (2010)

I was diagnosed early

1. My loved one was diagnosed early and the medical professionals involved were proactive in taking my views and knowledge into account to assist them and to help me support my loved one.

2. I was made aware early on about the importance and implications of Lasting Power of Attorney, and received timely advice to enable our family to support our loved one in making decisions about the future.

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

3. I and our family/support network are considered and consulted by those who provide treatment and support for our loved one.

4. I am consulted about my loved one’s care and there is an assumption of partnership in care even when there was not enough time to put a Lasting Power of Attorney in place before the advance of their illness.

Those around me and looking after me are well supported

I am treated with dignity and respect

5. I and my loved one are treated with dignity and respect. My role as a carer is respected.

6. My caring role is supported even when my loved one can no longer empathise with me and understand our interdependence.

I know what I can do to help myself and who else can help me

I can enjoy life

7. I am enabled to pursue my own enjoyment of life with appropriate support for our caring arrangements.

8. My community will be supportive of my role in caring for my loved one. We will be included in and feel part of the community we live in.

I feel part of a community and I am inspired to give something back

> I am confident my end of life wishes will be respected. I can expect a good death.

9. I will be included in decisions about my loved one’s end of life care as someone who has their best interests at heart.

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.

5.2 Respite

5.2.1 As well as identifying that carers need to be more involved in discussions about services for the person they care for, the Carers Joint Needs Assessment acknowledges that people living with dementia need a wide range of support services to help them stay at home including giving respite to their carers. Respite is vital since one third of carers for people living with dementia report being depressed and having a poorer quality of life than other carers. Evidence to the review also supported the findings of a 2008 survey by the University of Kent that 50% of Kent carers (including for people with dementia) said that their own health was adversely affected by caring duties and almost as many had serious health issues of their own such as a long standing illness or disability.

5.2.2 Respite of all kinds is crucial to enable carers for people with dementia to address their own health and wellbeing. Respite should include places where people can go together as a couple, day care and particularly respite at home. Respite needs to be flexible enough to meet the needs of people with younger onset dementia and also responsive to cultural and other factors.

5.2.3 NICE Dementia Quality Standard 10 says that: Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

5.2.4 As well as experiencing difficulties obtaining respite, particularly if planned in advance, carers felt that the respite provided was not sufficiently person-centred to meet their loved one’s needs or flexible enough to meet their own needs. Increasingly evidence is pointing towards the need for relationship-centred dementia care which supports and enhances the role of carers.[72]

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[72] NICE (2006)

"Any respite care seems to be arranged around group activities, which as J would not have taken part when well, he certainly won't now."
Joan Edwards, Carer – written evidence

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

"I would like respite care so I could stay at home and J could go somewhere to be looked after. This is proving difficult as the local mental health team could not persuade J to go last summer when my health let me down. They therefore announced they could not make him go, and so left him alone in the home overnight. They said that the only way to get J into care was to leave him alone at home and wait for a disaster to happen. Obviously I cannot do this."
Carer – written evidence

5.2.5 Feedback from carers, including directly to the Select Committee shows they would like access to respite:-

- to allow them to take time to attend hospital and GP appointments as well as important family occasions
- to cover in the case of a emergency; and
- for a planned ongoing pattern of short breaks

5.2.6 Evidence to the Select Committee suggests that current respite and day care arrangements are not meeting people's needs and that the recent closure of some facilities has made the problem worse and heightened people's fears that they will be unable to access suitable provision locally.[73] It was specifically highlighted to the Select Committee that Age Concern Centres in Ramsgate and Broadstairs are closing, despite being well used by people in Thanet.[74]

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[73] Deborah Connolly, Consultant Psychiatrist for Older People, East Kent - Hearing 8th April 2011
[74] Dr Sam Roberts, Clinical Psychologist – written evidence from Home Treatment Service/Older People's Psychological Services CMHTOP

5.2.7 Action has already been agreed to ensure that the 37 respite beds lost through KCC home closures are reprovided and the procurement of a total of 103 short term beds through block contracts at an estimated cost of £2.2million per year will shortly be implemented.[75] Funding for these beds will be a mixture of existing monies (DH funding + KCC money which would have been spent on direct provision) and new funding from the Department of Health (a proportion of a total £407k from Kent Primary Care Trusts.)

5.2.8 The new KCC short breaks policy with regard to planned and unplanned respite will be in place by October 2011. It will cover breaks of short duration (e.g. half a day) up to two weeks though the current draft policy wording says 'This policy is for carers and services users who due to urgent circumstances require access to a short term bed of up to 6 weeks. Most short breaks will be purchased through a Personal Budget.

GOOD PRACTICE AND INNOVATION

DEMENTIA CRISIS AND EMERGENCY RESPONSE SERVICE

A service has been piloted in West Kent for people with a known or suspected dementia and complex needs. The service was commissioned by Kent Adult Social Services (now part of the Families & Social Care directorate) on behalf of the West Kent Primary Care Trust (PCT).The service, provided in West Kent by Meritum, can provide intense support for up to 6 weeks to people living with dementia and their carers for example to help when a carer becomes ill and is unable temporarily to provide their usual level of support, thus helping to avoid untimely admission to a hospital or care home. At the time of publication of the Kent Carers' Annual report, the service had supported 130 people to remain in their own homes and having demonstrated its effectiveness, the service is now to be procured for East Kent with funding from the Department of Health; at no cost to people using the service.

Crossroads Care West Kent, Carers FIRST and the Alzheimer's Society have also provided emergency and crisis response services for those with dementia and their carers, helping 115 families to cope at home rather than resorting to hospital or care home admission.
Kent County Council (2010)

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[75] Newsam, M (n.d)

5.3 Carers' Assessments

5.3.1 A variety of legislation supports carers' rights including the rights of those providing regular and substantial care to a carer's assessment.[76]. Carers' needs may be assessed as critical, substantial, moderate or low and relate to the degree of risk suffered. 'Risk' is judged according to (in the case of 'critical' only) whether the carer's life is threatened and otherwise to the degree to which the carer's own health; autonomy; ability to cope with domestic routines and ability to maintain other social support or relationships (including work) are affected.

5.3.2 As part of the implementation of the Adult Carers' Strategy, KCC are developing the carers' assessment policy and in fact have a statutory duty to assess carers' needs. However, KCC has no statutory duty with regard to the *provision of services* to carers unless a critical risk is identified, in which case there is an obligation to make 'an appropriate response to address this risk'[77]. Carers for whom the risk is assessed as 'low' will be directed towards voluntary sector carer support services; others may be offered a service or one-off payment. Carers' Assessments can take up to 10 hours (including travel time) and KCC is exploring whether in future they could be carried out more effectively by voluntary sector support organisations.[78]

5.3.3 Two further issues highlighted by evidence to the review are that, firstly, carers for people with dementia are often unaware of their right to a carers' assessment and secondly, there is no financial help (e.g. to pay for respite) if the person cared for is self-funded. Home-based respite from private providers can cost around £700-£1500 per week which is likely to be out of reach for many people of ordinary means. In 5.5 Shared Lives Schemes are considered and Members feel these have potential to be developed with a community focus so that people who are self-funded could have access to less expensive, but personally tailored respite.

5.3.4 Carers receiving an assessment have the option of undertaking an introductory workshop and training offered by KCC in partnership with Carers Matter (in Kent) CIC. The 'Caring Confidently' training, takes place at venues throughout Kent. It is provided free of charge and covers such topics as coping with stress, eating healthily and identifying available support. Carers who spoke to the Select Committee highlighted the need for such training, emphasising that even those people who are 'natural carers' often have little idea of the challenges they will face.

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[76] Current KCC policy and standards with regard to carers' assessments can be found online at: https://shareweb.kent.gov.uk/Documents/adult-Social-Services/carers/carers-assessment-policy-and-service-standards-2009.pdf

[77] Janice Grant, Senior Policy Manager - supplementary written evidence

[78] Naomi Hill, Team Leader – Deafblind - hearing 16th March 2011

GOOD PRACTICE AND INNOVATION

LIFE SKILLS TRAINING

As part of their carer support services Age UK in Canterbury provide a One-to One Dementia Outreach Service. They were aware of the highly complex and emotive issues that family carers for people with dementia have to deal with on a daily basis and wished to find ways of supporting them. As a result Age UK Canterbury identified a form of counselling known as Life Skills Training which focuses on stress management.

The training is designed to help carers to manage stress so that they can cope better with their caring role, supporting them, their loved-ones and important family relationships.

Age UK Canterbury ran an initial course for 12 carers over a six week period and it was so successful that six further courses have been run locally.

The course addresses issues including:

- Self esteem – its importance, the reasons for low self esteem and how to improve it
- Listening skills
- Recognising strengths and qualities
- Recognising aggressive, passive and assertive behaviour
- Assertiveness skills
- Recognising stress and how it affects the body
- Relaxation exercises

Feedback from carers showed that they found the course to be excellent; surpassing their expectations. Carers also benefitted from the support of their peers in the group and the trusting relationships that developed. Some attendees formed friendships and supportive groups beyond the course itself.

Key benefits identified by course participants have included:

- Being better able to cope with stressful situations
- Finding the strength to carry on
- Being part of a network of support (continuing on after the course)
- Increased self-confidence
- Knowing how to relax
- Feeling more positive about the future

Sources:
Judy Ayris, Dementia Outreach Service for Carers, Age UK, Canterbury - written evidence;
Marie Miles, Life Skills Training Facilitator – written evidence

5.4 KCC Carers' Leave Policy

5.4.1 For its own staff, KCC currently has a Carers' Leave scheme which offers 5 days leave per year at a manager's discretion (in addition to current leave entitlement) to enable caring duties to be carried out. Guidance refers to a range of situations to which carer's leave may apply; however the examples given (shown below) are of a short-term nature:

- Providing care to my partner after a planned operation
- Caring for my child who is ill
- Responding when my parent falls and breaks their leg
- Taking my disabled friend for hospital treatment

5.4.2 There is no explanation of how a longer-term caring situation might best be managed and some clarification in the guidance may be of benefit to both carers and managers.

5.4.3 Carers who care for a person disabled by a degenerative condition such as dementia are protected from discrimination by the Equality Act 2010 (through their association with a disabled person). KCC staff policies take account of the Equality Act and the protected characteristics of carers by allowing an additional 5 days' leave and additional leave as required, at managers' discretion. This is line with Bold Steps for Kent: To tackle disadvantage, since Carers are a group who are often less able than other people to access employment, education and other opportunities.

5.5 Shared Lives Carer Schemes

5.5.1 Shared lives carers across the country provide small-scale community based care to adults, including older people with dementia, to support their independence and contribute to more personalised social care. KCC currently operates an Adult Placement Scheme to provide respite for adults with learning disabilities but has not so far operated such a scheme for people living with dementia. As noted, people with learning disabilities can expect to live longer but in their 50s have a higher incidence of dementia than other people.

5.5.2 There are around 10,000 carers involved in Shared Lives schemes in the UK, a proportion of whom (around a third) are Members of NAAPS (originally the National Association of Adult Placement Schemes).[79] Schemes are relatively simple to set up: Advertising is launched to invite people interested in becoming shared lives carers to come forward and once a bank of carers has been established, there is a matching process which involves assessment by a Care

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[79] Shared Lives arrangements are regulated in England under the Health and Social Care Act 2008.

Manager. The Shared Lives carer then begins to build a supportive relationship with their ‘client’ and offers their family home as a resource.

5.5.3 A business case was put together by Improvement and Efficiency South East and NAAPS demonstrating that arrangements with regard to older people can generate around £23,400 savings per year to Local Authorities compared with other forms of support.[80]

5.5.4 Shared Lives could provide a community based respite option for carers and people living with dementia helping to address the absence of out of hours respite beds in Kent[81] as well as the rarity of respite beds generally which leads to people being placed out of area.[82] For a person living with dementia and their carer it is envisaged that after an initial period of relationship-building, a Shared Lives carer could provide respite over an extended period, assuring better continuity than with other types of respite care. At the point when such arrangements no longer meet the needs of the person living with dementia, the supportive relationship can potentially continue. Other schemes report the building of lasting supportive friendships.

> ***“There can in some cases be waits of over a year for a short period of planned respite.”***
> Elaine Oxley, NHS Carers’ Support Project, personal communication

5.5.5 A number of Local Authorities have put Shared Lives schemes into place and brief details of the Leeds and Falkirk schemes are shown on the following page. Some Local Authorities elect to outsource schemes rather than running them ‘in-house’.

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[80] NAAPS UK Ltd (2010)

[81] Linda Caldwell, Older Person Commissioning Manager, NHS Eastern & Coastal Kent – Training Session 26th January 2011

[82] Jamie Waldie, Dementia Support Worker, Crossroads Care – Hearing 5th April 2011

GOOD PRACTICE AND INNOVATION

Leeds: Shared Lives breaks

Leeds Shared Lives offers different types of flexible support based on individual needs. Breaks can take place in the home of the Shared Lives carer or at the client's own home, whichever is preferred and could be:

- a short break overnight, for a weekend or part of a week
- support during the day for a few hours
- night awake service, so that the person who looks after you can catch up with their sleep

GOOD PRACTICE AND INNOVATION

Falkirk: Time to Share scheme

The scheme was set up 15 years ago under Falkirk Council's Joint Dementia Initiative, a multi agency scheme to improve the independence and well being of people with memory problems. Time to share provides short breaks for people with dementia in the homes of Shared Lives carers. Key points of the scheme:

- Personalised, flexible service enabling people to do normal everyday things.
- Gives the carer a break but is as much for the person with memory problems
- Consistent form of support
- Currently there are 12 service users who can use the service for 6 weeks a year in periods of one to fourteen nights.
- There are 5 Time to Share carers, some single, some couples
- 2 of the Time to Share carers accept couples (both person living with dementia AND their carer together)

5.5.6 As noted, KCC's Adult Placement Scheme currently supports people with a learning disability. It is anticipated that some additional capacity would be needed during the initial stages of a Shared Lives scheme in Kent for people living with dementia, to enable sufficient assessments to be carried out so that a 'bank' of suitable Shared Lives carers could be built up. There is some existing capacity in the West Kent Adult Placement Team and this could lend itself well to a pilot scheme to test the suitability of such a scheme to meet the needs of, for example, BME carers and people living with dementia. Swale is a further area where it is reported there is a lack of services tailored to BME carers and so a pilot scheme could also test whether this could bring about a reduction in health inequalities in the area.

5.5.7 The Personal Social Services Research Unit (PSSRU) at Kent University intend to submit a proposal which, in partnership with a number of local authorities (including potentially, Kent) will evaluate Shared Lives schemes for particular groups of people and this could include people with Dementia. This Select Committee could contribute by informing research questions asked by the review.

5.5.8 Members have heard that people in rural areas can find themselves doubly disadvantaged if suitable respite is not available locally and believe that there would be merit in testing the principle of voluntary sector dementia support organisations administering personal budgets for groups of people in an area, in order to provide more effective, personalised support.

5.6 Advocacy

5.6.1 The role of IMCA (Independent Mental Capacity Advocate) was introduced by the Mental Capacity Act 2005.

> ***'Advocacy provision is often recommended or seen as good practice. The National Dementia Strategy for England and Wales recognises the role of independent advocacy as part of a range of community support services. The Mental Capacity Act recognises the valuable role of independent advocacy for people who may lack capacity. The government's policy on Personalisation aims to encourage people to have more control over their own lives and care needs but for many this is unobtainable unless necessary support is provided.'***
>
> Dementia Advocacy Network (2011)

5.6.2 Objective 6 of the National Dementia Strategy is to 'Improve community personal support services. Independent advocacy services were highlighted as one of the services required in KCC's 2009 'Dementia Healthcheck' report[83].

5.6.3 Independent dementia advocacy services were commissioned in West Kent in response to a recommendation made by the Care Quality Commission following inspection of Kent & Medway NHS and Social Care Partnership Trust's Jasmine Ward and a review of adult advocacy services. The original KCC contract for one year's advocacy services in West Kent was for £50,000 and in the first 10 months of the service (which commenced in May 2010) more than 80 people

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[83] Thomas-Sam, M (2010)

were helped.[84] The service is currently provided in West Kent by Invicta Advocacy who help people with dementia, at no cost to users of the service, by speaking up on their behalf issues including:

- present and future care
- safeguarding
- access and entitlement to services
- ensuring that people in their life are acting in their best interests and keeping them central to all decisions (if lacking capacity)
- human rights

> ***"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."***
> Sally Parsonage, Carer – written evidence

5.6.4 The Carers Annual Report 2009/10 indicates that NHS funding helped to provide 'advocacy and counselling services by establishing a carers' centre contact point in Dover' which assists carers for people with dementia. The Select Committee has also received evidence of other advocacy activity in the County, such as that provided by CARM (Caring Altogether in Romney Marsh) to older people who have been abused.

5.6.5 Organisations such as Age UK and carer support organisations such as Maidstone and Malling Carers Project assist carers including carers for people living with dementia by providing support at meetings with professionals, writing letters and resolving problems.

5.6.6 Though an Advocacy Strategy is being developed by KCC with the involvement of the voluntary sector there is currently a lack of advocacy services capable of responding and intervening on behalf of people with dementia in East Kent and the Select Committee has heard of the frustration one carer felt when contacting the service advertised on DementiaWeb, only to find it did not cover the part of Kent where she lived.

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[84] Kent Carers Annual report 2010/11

GOOD PRACTICE AND INNOVATION

Advocacy for Jane*

Jane was an elderly lady with dementia who was taken to a busy acute hospital following a fall. She was assessed as not having capacity to decide on her future care. Her husband was elderly and her grown up children were adamant that he could not look after her any more. Jane was equally adamant that all she wanted was to go home and be with her husband. She told the advocate this on more than one occasion. The advocate, invited to the Best Interests meeting, was able to speak up for Jane of her wish to be with her husband at home.

It was equally clear that Jane's husband could not care for her alone (which is why her children felt strongly that their Mum should go into a care home). The decision was that Jane went home to be with her husband and social services ensured that sufficient care was put in to help her husband look after her. Jane's wishes and feelings were respected; the local authority saved many thousands of pounds by not placing Jane in a Care Home and the NHS were able to free up the hospital bed more quickly.

*Source: Sue Scanlan, Director, Invicta Advocacy Services – written evidence *(name has been changed)*

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.**

5.7 Decisions about the future

5.7.1 NICE Quality Standard (no. 5) indicates that people with dementia, while they have capacity, *have the opportunity* to discuss and make decisions, together with their carer/s, about the use of:

- advance statements

- advance decisions to refuse treatment
- Lasting Power of Attorney
- Preferred Priorities of Care

'The thing is, once you've spoken about these things (as hard as it might be), you can put them away and focus on enjoying things.'
The National Council for Palliative Care (2011)

"It is possible to get Lasting Power of Attorney prior to diagnosis and when the person no longer understands, that is when it should be registered".
Sandie Crouch, Assessment and Enablement Worker – Hearing 5th April 2011

Mental Capacity Act 2005

The Mental Capacity Act 2005 (MCA) applies to people aged 16 and over in (England and Wales) who may lack the capacity to make decisions because of illness, learning disability, or mental health issues including dementia. The kinds of decisions it covers include those about personal care, healthcare, property and finances. A person's mental capacity, particularly with certain types of dementia, can fluctuate over time but generally speaking a person has mental capacity if (at a specific time) they can understand information, retain it, weigh it up and communicate their wishes by whatever means they can.

The Act put a number of important safeguards in place including making it a criminal offence (punishable by 5 years imprisonment) to wilfully neglect or mistreat a person who lacks mental capacity. When it came into effect in October 2007, the MCA introduced Lasting Powers of Attorney to replace Enduring Powers of Attorney which enable a person (while they have capacity) to nominate a person or persons to make decisions on their behalf.

5.8 Lasting Power of Attorney

5.8.1 The Map of Medicine[85] clinical guidance on the assessment of dementia indicates that GPs should discuss early on with patients 'and their family or carers', advance statements, advance decisions to refuse treatment and Lasting Power of Attorney (LPA) as well as a Preferred Place of Care Plan (including end of life care). However, people with dementia who do not receive an early diagnosis may not have the opportunity to make important decisions for themselves about future care and finances if they are already deemed to have lost mental capacity. Carers can then face considerable difficulties over and above the usual challenges of their caring role.

5.8.2 The Select Committee heard compelling evidence from carers and former carers for people living with dementia about the impossible position they can find themselves in when trying to carry out the wishes of a loved one without the correct authority in place. The views expressed to the committee echoed the findings of a recent report by the National Council for Palliative Care.[86]

> ***"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."***
> Anna Ramsay, Senior Practitioner, Assessment and Enablement Team – Hearing 5th April 2011

5.8.3 As well as late diagnosis, a lack of knowledge and understanding about the options regarding LPA or concerns about cost can also cause delays and lead to missed opportunities for discussions about the future to take place. It is particularly important for people living with dementia to be able to sort out financial and legal matters as well as those in relation to their health and care. People may wish to make a Will, set up a Trust and consider Lasting Powers of Attorney for both their Property and Affairs and Personal Welfare. The latter must be registered at the Office of the Public Guardian (OPG) before they are valid though Enduring Powers of Attorney (in relation to finance and property) signed before 1st October 2007 are still valid, without registration.

> ***"EPA cost £1000 some years ago, which many people could not have afforded. ... I did this early on because of experience with a relative."***
> Carer – Hearing 9th March 2011

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[85] The Map of Medicine (2011)

[86] The National Council for Palliative Care (2011)

5.8.4 The complexity of the applications process was highlighted to the Select Committee, in evidence from Citizens Advice Bureaux, as one of the dementia-related issues that people seek advice on nationally. It was also reported directly to the Select Committee that mistakes made in the application can cause delays, difficulties and added expense in some cases. In addition, if no EPA or LPA is in place the powers of the Court of Protection can be invoked where there are Mental Capacity issues, causing problems and added expense for carers trying to deal with the affairs of a person living with dementia, whilst at the same time providing vital care and support.

> ***"… people want their child to have a Lasting Power of Attorney but often when the son/daughter sign up for this they do not realise the implications."***
> Sandie Crouch, Assessment and Enablement Worker – Hearing 5th April 2011

5.8.5 As well as Citizens Advice Bureaux there are many sources of advice on LPA for people living with dementia and their carers including DementiaWeb, KCC, KMPT and voluntary sector support organisations. There is also comprehensive information provided on the websites of the Office of the Public Guardian and Direct.gov. However there is probably a low level of awareness of it among the general population and evidence to the Select Committee would indicate that considerable hardship and difficulties could be avoided if people were strongly encouraged to think about their future choices early on, certainly at the onset of any memory problems and at the latest, at diagnosis.

> ***"D was diagnosed with Alzheimer's 7 years ago. One of the first things he did was to sign Power of Attorney over to three of his children. Dad knew that his family would all work together to do the very best for him."***
> Lorraine Hambidge, Carer – written evidence

5.8.6 People who are not able to access the internet are at a considerable disadvantage compared to those who can access guidance materials online.

5.8.7 Even where a person has been granted an LPA, there can be additional hurdles to negotiate. For example, some High Street Banks still require people to go through internal banking procedures and extensive form-filling which should not be necessary. People experiencing this may complain to their bank and if a satisfactory response is not received within 8 weeks, the next step is to contact the Financial Ombudsmen. However, this is an additional and unnecessary burden for carers who are caring for and supporting a loved one with dementia.

5.8.8 A better understanding of the implications of LPA by the general population and by banks in particular, could prevent some of the problems highlighted by carers to the Select Committee. According to the British Banking Association there should be no problem in getting banks to recognise LPA (and EPA); the issue is one of staff awareness and training.[87] The British Banking Association is aware of the need for staff training on this issue and have recently formulated a Third Party Authorisation Framework to provide guidance.[88]

5.8.9 Some banks are setting a positive example by making personally tailored arrangements to support customers with dementia. One respondent to the recent All Party Parliamentary Group on Dementia told of positive efforts by a High Street Bank to enable his father to withdraw on demand up to £10 per day, enabling him to continue to live normally, but with the added protection that Clerks would alert the carer if more than one withdrawal was attempted in a day.[89]

5.8.10 KCC is fortunate to have an award winning Legal Service team and Members believe there is merit in exploring whether the team could provide a competitive service with regard to assisting e.g. adult social care clients, with LPA, provided there were no conflicts of interest.

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. (This is linked to R13 on information and signposting.)

5.9 Protecting relationships – behaviour that challenges

5.9.1 It has been highlighted that an inability to manage behaviour that challenges often leads to crisis for the person living with dementia whether at home or in residential care (and can lead to sectioning or hospitalisation). In fact it has long been recognised that a high proportion (some sources indicate 90%) of 'catastrophic' behaviours of people living with dementia originate in some way from a trigger from the environment or (misunderstanding) the action of carers[90].

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[87] Argun Singh-Murchelle, British Banking Association – written evidence

[88] Ibid

[89] All Party Parliamentary Group on Dementia (2011)

[90] Brawley, E. (1997)

5.9.2 The Select Committee heard from carers and former carers who have battled to look after their loved ones at home without any help to deal with aggression and violent behaviour. One former carer described how simply moving an everyday object could lead to a huge outburst and recriminations, though with empathy and the benefit of hindsight it can be seen how, in trying to make sense of a world that had become confusing, a change from the 'regular' could provoke such a reaction. Out of loyalty to their loved-ones as well as fear of the outcome of seeking help/reporting incidents carers in this position tend not to seek help until they become desperate and reach an irredeemable crisis situation.

5.9.3 Care givers subjected to aggression can suffer considerable distress as a result of such crises. The provision of proactive support and a better understanding of the triggers for aggression (by both family and professional care givers and other agencies) is required so that carers are not left to cope alone with loved-ones who may themselves be suffering distress; and people living with dementia in residential settings receive appropriate support and are not subject to unplanned moves due to staff's inability to cope.

> ***"Dealing with aggression on a daily basis is very hard. When you go to professionals they tell you to walk away. When there is an argument or aggression, their answer is medication or walk away."***
> David Russell, Former Carer – Hearing 9th March 2011

> ***"For the last two years of his life I was a prisoner, not only having to be at home but in the same room. He hit me because he thought that I was being unfaithful, he then thought that the bruises were caused by my lover beating me up."***
> Jeanne B, Former Carer – Hearing 9th March 2011

"One night it came to a crisis, I couldn't stay in the house any longer, I went to my neighbour's and called the police who came back home with me, it took 6 police officers to get him into the van. He was sectioned and taken to a psychiatric unit."
Former Carer – Hearing 9th March 2011

5.9.4 A joint Police, Social Services and Health Protocol (2004) exists for dealing with cases of domestic violence where vulnerable adults are involved. This policy relates to vulnerable adults who are subjected to violence. There is a need for a protocol which takes account of the fact that frustration which manifests as aggression is a well known feature of some people's experience of dementia, which suggests ways in which carers may be supported to avoid it or deal with it and ways in which emergency services may respond appropriately and access advice.

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.

5.10 Using Assistive Technology to support caring relationships

5.10.1 Assistive Technology is defined as "any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed."[91] Telecare is the use of assistive technology, usually in the form of sensors or other monitoring devices to assist people to live more safely in their own homes, often linked to response systems in the event of a problem being alerted.

5.10.2 The review has not considered Telehealth (which has been trialled alongside Telecare in Kent and elsewhere, with regard to people living with dementia though Members learned that there have been successes elsewhere). Telecare should not be confused with 'Lifeline' which is a community alarm system offered by District and Borough Councils and another way in which people can be supported to live at home.

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[91] Royal Commission on Long Term Care (1999)

5.10.3 Telecare is provided free of charge to social care clients in Kent meeting eligibility criteria at the moderate level; while some other authorities levy charges and have set their eligibility at the critical or substantial needs level. This enables support for people to remain in their homes to be accessed earlier on[92].

5.10.4 KCC implemented three pilot schemes in 2004, investing £2.25m and by 2009 when a two year trial funded by the Department of Health began, there were already 1100 people benefiting from technological assistance of various kinds, 93% of whom felt safer and more independent as a result. The more recent national trial, known as the Whole Systems Demonstrator Project, has involved 6000 participants, 470 of whom were carers, testing whether Telecare and Telehealth could enhance the safety and security of the home environment for the person being cared for, with the added benefit of assisting carers to balance caring with their own work responsibilities; helping employers to retain skilled and experienced workers.

5.10.5 A report evaluating the national pilots is expected later this year though the Select Committee learned that there had so far been no particular focus in the Kent project on using Telecare to support people living with dementia. This is however an intended area of focus for the future. One of the ways in which people with dementia and their carers can be supported with technology is to provide a safeguard for people who wander. The Select Committee heard from several people who were already using GPS technology to ensure they could find loved-ones who tended to wander as part of their experience of dementia. One carer who provided evidence to the review had installed a camera which could alert her (by internet) to callers to her father to ensure that he did not let anyone into the house that he shouldn't (following experience of callers who tried to exploit his vulnerability).

> ***"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."***
>
> Lorraine Hambidge, Carer – written evidence

5.10.6 Use of cameras and tracking devices to protect people are representative of many ethical dilemmas that may arise from the use of Telecare to augment the provision of social care services. Concerns centre on autonomy, mental capacity

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[92] Hazel Price, Programme Manager, Kent Whole Systems Demonstrator Project - Hearting 8th April

and consent but these are balanced by the need, and duty, to safeguard and protect people who are vulnerable; issues of particular relevance when technology is used to safeguard people with dementia.

> ***“Questions have been raised as to whether we are infringing on his ‘human rights’. My daughter says ‘that’s my ‘ASBO Grandad’ due to his tracker. But we know that he would not mind us doing these things to keep him living in his own home which we know was his wish.”***
> Lorraine Hambidge, Carer – written evidence

5.10.7 In Kent there is as yet no ‘response’ system to monitor/detector-type assistive technology and Members believe that this may be one very valuable development arising out of KCC’s current experience of Telecare. Response services may be procured from the private or voluntary sector. Members are also keen that there is investigation into the ways that different types of technology are already being used by carers to assist them to look after loved ones living with dementia. Carers have, through necessity and ingenuity found solutions which ‘work for them’ and many more people could benefit from sharing that knowledge.

5.10.8 The Select Committee have learned during the course of the review, about several devices which have already been found by carers and family members to be useful in supporting the care of people living with dementia. They range from very inexpensive (universal devices such as gas detector alarms at a cost of around £10) to moderately expensive but very specialised equipment which has been designed to address wandering in order to preserve people’s freedom to move around as they choose, but with extra safeguards. Some can be purchased outright and some require monthly contracts.

5.10.9 A new Department of Health (DH) guidance pack for commissioners of dementia services acknowledges the paucity of evidence specific to assistive technology and dementia but acknowledges the potential for it to assist with ‘safer walking’.[93]

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[93] Department of Health (2011)

GOOD PRACTICE AND INNOVATION

The Carer’s Watch

The Carer’s Watch (2find-me watch) was developed in Australia by a man whose father developed frontal lobe dementia after emigrating, and had become lost on several occasions through wandering.

It looks like an ordinary digital watch but can be used like a phone to receive incoming calls and also to contact loved ones at the press of buttons A and B which can be programmed with relative/carers’ numbers. There is also an emergency button which, if pressed, triggers the sending of texts to up to five contacts giving the location of the wearer. The watch is easy to remove but can be secured in place if necessary. A range of other ‘reminder’ and ‘health monitoring’ uses are also being explored and the watch is available so far in Australia and the UK in wristwatch form but can easily be adapted to be worn as a brooch or pendant .

There is a one-off set up fee of £290 for the watch and thereafter, the monthly cost of services is £32 (comparable to a mobile phone).

Source: Michael O’Dell – Hearing 29th March and written evidence

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’.

6 INFORMATION AND SIGNPOSTING

6.1 Information about dementia, services and support

6.1.1 NICE Quality Standard 3 says: People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.

6.1.2 National Dementia Strategy (NDS) Objective 3 is that there should be: Good-quality information for those with diagnosed dementia and their carers 'on the illness and on the services available both at diagnosis and throughout the course of their care'.

6.1.3 Despite these standards and objectives, evidence to the Select Committee indicates that finding information about services (and obtaining them) for the person they provide care for as well as for themselves is still one of the greatest challenges for carers for people with dementia and for people with dementia themselves.

6.1.4 Currently, people in different parts of Kent will have access to information about dementia and dementia services and support from numerous sources including NHS and private health organisations, Social Services, Voluntary Sector organisations, and numerous national online sources. Members have heard about excellent examples of local information gathered together in booklets or folders provided by voluntary sector organisations in various parts of Kent, for example the Care Navigation Service provided by Thanet Community Support Project which has a file assembled over a two year period, and a laptop on hand so that people can access online-only resources. However, there is no consistency of provision and no printed/printable guide to services and support that people living with dementia anywhere in Kent, and their carers, could access which also informed them about what is available in their local area.

6.1.5 Though internet use in the UK is steadily increasing, it is still strongly correlated with age and 60% of people over 65 still do not access the internet.[94] Evidence from Maidstone & Malling Carers Project would indicate that carers may be even more dependent on non-web information sources since only 60 of 1600 (under 4%) of people they serve (which includes carers for people with dementia) elect to receive information by email. Despite this, the internet remains an important source of information which can often be accessed by friends, relatives or support organisations on behalf of people with dementia and carers seeking information.

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[94] Office for National Statistics (2010)

6.1.6 DementiaWeb[95] is a comprehensive source of information on all aspects of dementia. It was launched in May 2010 and in the first 10 months of its operation had almost 37,000 visits and the number of pages viewed was almost double that. There are links on the website to the organisations shown below as well as the Dementia Services Development Centre at Canterbury Christ Church University and the Alzheimer's Society who have leaflets on all aspects of dementia. Having been set up in West Kent, DementiaWeb has more information about support in that part of Kent but has begun the task of gathering Kent-wide resource information. Organisations featuring on the website are approached on a monthly basis for updates to ensure that the site is as up to date as possible. The Select Committee would urge dementia support organisations all over the county to contact DementiaWeb so that they can be featured. People will then be assured of finding a list of local facilities/services on the website when they carry out a search using their postcode.

DementiaWeb Associate Sites

- The Alzheimer's Society
- Alzheimer's and Dementia Support Services
- Guideposts Trust
- Kent County Council
- Kent Adult Social Services
- Kent and Medway Partnership Trust
- Medway Council
- NHS Medway
- NHS West Kent
- NHS Eastern and Coastal Kent

DementiaWeb External Links

- Directgov
- Dementia UK
- Department of Health
- Age UK
- The Princess Royal Trust

Allied to DementiaWeb a 24 Hour Dementia Helpline has also been set up by the Alzheimer's Society and Alzheimer's and Dementia Support Services.

24 Hour Kent and Medway Dementia Helpline 0800 500 3014

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[95] Online at: http://www.dementiawebkentandmedway.org.uk

6.1.7 Members believe that a more standardised approach to information provision across agencies could result in less duplication and more consistency. Ideally, people living anywhere in Kent should be able to access printable generic information about dementia as well as information specific to the district in which they live.

6.1.8 The Early Intervention Project in North West Kent (outlined on page 47) has successfully demonstrated how people with memory problems can be provided with information and linked in to local support services before (or in the absence of) a diagnosis of dementia, via their GP surgery. In East Kent, in particular, GP Practices are largely unaware of support services in their local community. Linking DementiaWeb to GP practice websites could help to remedy this[96]. A similar commitment to early intervention throughout Kent, perhaps linked to the National Health Checks scheme, could have the multiple benefits of picking up problems early on. Utilising a nurse-led service within practices or facilitating assessments within practices by the Community Mental Health Team could ensure that everyone with identified needs in relation to memory problems is signposted to local help and support.

6.2 Information for self-funders

6.2.1 The majority of people living with dementia will not be eligible for support from Social Services i.e. they are self-funders. Evidence from a number of self-funded individuals who have approached KASS (now FSC – Adults) for information indicates that there is no co-ordinated response and no standard set of information that is routinely offered or provided. Some participants in a consultation event said that they had been offered no information when approaching KCC’s call centre for help once they mentioned they were self-funded.

6.3 Health Referral Scheme – adult education

6.3.1 People who had been recently diagnosed about dementia spoke to Members about their views on how information should be provided to them and as might be expected individuals varied in their preferences. However, one thread running through those views was that having something to do, a task which could occupy and keep them busy at this difficult time, was very helpful. In the early stages of dementia people are very capable and in many cases keen to continue with as many as possible of their usual activities and indeed can benefit from doing so. People’s interests will necessarily vary but Members believe that sources providing information on dementia should also signpost to positive activities

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[96] Dr David Kanagasooriam - written evidence

such as local leisure opportunities and the range of evening classes that might be enjoyed for example in the arts and music as well as those concerned with sport, fitness and staying well physically.

6.3.2 Maintaining hobbies and pursuing interests can be expensive and some assistance with the cost of evening classes is available in Kent through a Health Referral Scheme. Under the 2011-12 scheme people who are referred by their GP, nurse or other health practitioner as someone who may benefit from an adult education course, can get advice via informal interview on the types of courses that interest them and receive a 50% discount. The discount is applicable to someone who has received a diagnosis of dementia and any carer in need of respite from caring responsibilities could receive the same consideration. In addition to this health-related discount, funding is available to subsidise people on low household incomes. Government funding can also be arranged for the provision of a Teaching Assistant or any adaptations that may be required in order to ensure those wishing to attend a course can do so.[97] Integration with other students is the norm and it may be of benefit for tutors to undergo dementia awareness training offered by KCC Learning and Resources in order to be able to offer an equitable service.

6.4 Libraries' work in support of people living with dementia

6.4.1 Kent Libraries are now developing an increasing range of services specifically aimed at enriching the lives of people who are living with dementia and the Select Committee was able to take part in an example of reminiscence work during a visit to a dementia café organised by the Alzheimer's Society. Members observed how a familiar or historically significant object could prompt memories and discussion, helping greatly with communication skills and maintaining individuals' confidence as well as providing entertainment and enjoyment. The benefits of reminiscence work in dementia are well evidenced; and many resources are available to facilitate it, for example using photos, scrap books and other types of memory work which can also provide an ideal opportunity for children to interact with their older relatives.

6.4.2 Libraries stock reminiscence boxes on a number of themes (Figure 14 on the next page) suitable for people with younger as well as older onset dementia. Boxes contain such items as books, DVDs, CDs, as well as posters, photos, toys, and other memorabilia.

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[97] Susannah Ireland, Partnership Development Manager, Community and Social Interest – written evidencce

Figure 14: Reminiscence Boxes maintained by Kent Libraries Service

1930's	Kentish/East Kent scenes
1940s	Kentish/Medway scenes
1950's	Kentish/Mid Kent scenes
1960's	Kentish/West Kent scenes
1970's	London life
1980's	Looking good
Around Britain	Men's lives
At home	Our neighbourhood
Beside the seaside	Sporting memories
Between the wars	Steam
Celebrations	Thanks for the memory
Childhood	That's entertainment
Christmas memories	The last 50 years
Comedy	The Royal family
Evacuees	The time of our lives
Growing up	Travel and transport
Highdays and holidays	Twentieth Century life
Hollywood	When the lights go on again
Hopping in Kent	When we were young
In the country/rural life	Women at War
In the kitchen	Women's Lives
Kent at War	World War II
Kentish scenes	World War II – Home front

6.4.3 The boxes are currently loaned for a nominal fee to 153 customers throughout Kent and Medway who use them to deliver their own reminiscence sessions in settings including care homes, sheltered housing schemes, day centres and hospices.[98]

6.4.4 With the benefit of a Member's Community Grant of £500, as part of the Kent Literacy and Reading Strategy, three sets of books have been purchased to be used for a Read Aloud Scheme in Canterbury for people living with dementia. A Reader Development Officer also offers training to enable volunteers to lead Read Aloud Sessions which have so far taken part at local dementia cafes. Canterbury Library is undergoing refurbishment and it is intended that sessions can eventually take part in the library, enhancing its role as a community facility.

6.4.5 Other Library services which are or could be developed to provide support and enjoyment for people living with dementia are:

- Work with the local museum to demonstrated how art can also be used as a prompt for conversation and reminiscence in this setting.
- Mobile Libraries
- Home Library Service run by volunteers providing regular visits to people who are housebound
- Audio books, bag books (multi-sensory sets with story 'props' for interactive sessions)
- Talk Time Groups weekly in each library to address social isolation (volunteer run)
- Silver Surfers (Web Wizards and Computer Buddies at most Libraries to provide assistance and monthly groups)[99]

6.4.6 The Select Committee would like to see this work extended to all Kent Libraries and consider that Talk Time Groups have the potential to be developed into Memory Clubs or Dementia Cafés.

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[98] Caroline Wareham , Customer Support Officer - Open Access – written evidence

[99] Daren Kearl, Community Development Librarian and Tricia Fincher, Service Development Librarian – written evidence and personal communication

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. (See also recommendation 8)**

> ***"I am fortunate in that I have always maintained a positive approach since being diagnosed. I achieve this by keeping active mentally and physically. I read quite a lot, enjoy a range of long standing hobbies – gardening, stamp collecting, word puzzles, walking, travel – in the UK and in Australia. I have also recently developed an interest in completing jig-saw puzzles and tracing my family history."***
> Keith Oliver – written evidence

6.5 Signposting – two different models of support

6.5.1 Arising out of the National Dementia Strategy and following consultation with professionals it was decided that two two-year pilot projects testing different ways of signposting people to information and support after diagnosis would be put in place. One pilot project concerned with information, advice and signposting was implemented in Medway and a second testing a model of peer support was piloted in the KCC area by the Alzheimer's Society (groups in Maidstone and Sevenoaks were visited by Members during this review). Both of these would inform the commissioning strategy for the future and the dementia pathway.

GOOD PRACTICE AND INNOVATION

Signposting 1 – The Medway Dementia Advisors Pilot Project

Beginning in 2009/10, Department of Health-funded Dementia Advisor services were piloted at 22 sites around the country. One such scheme was set up in Medway by the Sunlight Trust and its aim was to provide people who got in touch with a named contact or buddy (one of four advisors).

People attending the Memory Service and receiving a diagnosis of dementia were offered six sessions of psychological counselling and the intention of the pilot was that on completing the counselling, people would be handed over to the Dementia Advisor service where they would be offered a face-to-face visit. This contact would enable the Advisor to begin to build a relationship with the person to accompany them through their whole journey with dementia; and whilst it was primarily for them, it could assist carers too. The Advisor would be able to provide up to date information appropriate to each person’s needs and stage of dementia as well as, for example, regarding entitlements which they could help people to access and directing to other sources of information as necessary.

However KMPT who provide the Memory Service were reluctant to pass personal details on to the follow up service for reasons of confidentiality and this resulted in some people not receiving information and therefore not having their needs met. A booklet was produced by the Advisors which partially addressed this problem. The scheme worked more effectively as people got to know of its existence and self-referred prior to and post-diagnosis, as well as being referred by a GP, care manager or memory clinic, thus contributing to early diagnosis and support. At the time of writing, over 500 people are being supported by the scheme.

The pilot ended in May 2011; and the project has been extended until September while local and national evaluations are carried out.

Source: Maggie Luck, Sunlight Trust- written evidence & NHS Medway Operational Plan 2011-12

GOOD PRACTICE AND INNOVATION

Signposting 2 - Memory Cafes & Peer Support

Memory Cafes (sometimes called ‘drop ins’) are offered at various places across the county by voluntary sector groups and organisations – some have been running for around 8 years and have built up good community links, regularly attracting 40-60 people including people living with dementia, carers and professionals. These groups, such as one which Members visited at Newington Church in Ramsgate, do not require people attending to have a diagnosis of dementia and most incorporate informal peer support.

For example, East Kent Independent Dementia Support (EKIDS) now has 7 such groups per month at various locations across the area, designed to meet the needs of people of different ages, the person with dementia and carer together or separately according to people’s preference. There is also a separate monthly group just for carers where they can openly discuss any problems they may have, which is not always possible in the presence of the person they care for.

The Dementia Cafes set up by the Alzheimer’s Society as part of the National Demonstrator Pilot projects run on a ‘drop-in basis’ though they require attendees to have had a formal diagnosis of dementia. Peer Support groups have been set up as closed groups of 8-10 people. There are currently 4 – in Ashford, Dover, Maidstone, and West Malling, which meet every two weeks with the aim of:

- Offering mutual support
- Helping people come to terms with their diagnosis and live well with dementia
- Reducing social isolation
- Increasing access to information, tailored for individual needs
- Helping people to maintain independence and life skills, health and wellbeing
- Providing stimulating conversations

Members visited two groups and observed the high level of trust and respect which participants had developed for eachother and for the group facilitator.

Sources:
Visits to EKIDS and Alzheimer’s Society Groups

6.5.2 Having visited several memory cafes and peer support groups of different types, Members believe the existence of long-standing and well-attended groups is evidence of their success. Such groups provide an informal and ‘non-threatening’ environment in which people with dementia and their carers can gain support from their peers, socialise, as well as speak to representatives from organisations providing local support. For example one drop-in group which was visited (on spec) by a Member of the Select Committee had around 40-50 attendees among whom were various professionals on hand to give support and advice including an Admiral Nurse, Crossroads Care Liaison Worker, several representatives from East Kent Independent Dementia Support (EKIDS) who support the group, a Community Mental Health Nurse, Student Nurse and others. Members also learned that Community Police Officers, who know their communities well, are able to link people into local groups from which they may be able to gain information and support.

6.5.3 Community groups such as Rotary could have an important role to play in extending the network of support for people with dementia in Kent by developing memory cafes and indeed have expressed to the Select Committee a willingness to do so. REPOD (Rotarians easing the problems of dementia) have been involved in the setting up of Cafes in the West Country in response to an identified gap in services and have produced an excellent guide to setting up a memory café (focused on the West Country, but translatable to any other location) which provides guidance on setting up and running a café based on only five main ‘ingredients’:

- A co-ordinator
- Volunteers
- Premises
- Funding
- Involvement of Local Authorities, NHS Trusts and voluntary sector partners[100]

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[100] REPoD (2010)

6.5.4 During the course of this review Select Committee Members have already taken the opportunity to identify funding to support the continuation of an existing group in Kent and would strongly encourage anyone wishing to set up a group, in the first instance, to contact their local Community Engagement Manager who can put anyone who is interested in touch with their County Member and also advise on making bids for funding.[101] An example of this that has already led to increased support for people with dementia in the Canterbury area was highlighted earlier in this section and the Select Committee can see a clear route for assisting the development of a network of Memory Clubs or dementia cafes and embedding them in communities perhaps using existing library premises as resources where practical. This would also help to forge links between voluntary sector support, the availability of information and signposting resources, and enjoyable and entertaining social activities.

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.
(See also recommendations 6 and 11)

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[101] Your local Community Engagement Manager can be found by looking online at :http://www.kent.gov.uk/your_council/have_your_say/community_engagement.aspx

7 DEMENTIA CARE PATHWAY - FUTURE STRATEGY FOR KENT

7.1 Quality Care

7.1.1 The NICE 10 point Quality Standard for Dementia (Appendix 7) concerns how the following should contribute to Quality care:

- Training
- Memory Assessment
- Information
- Care Plan
- Decision making
- Carers' Assessments
- Managing Non-cognitive symptoms
- Liaison Services in hospital
- Palliative Care
- Respite

7.1.2 In addition to measures of quality care that the Standard sets out, a very strong message running through the evidence to this Select Committee from people living with dementia and their families has been that it is the quality of interaction and the relationship built with professionals and others involved in care and support, which has the most positive impact on people's experience and quality of life. Things people said they particularly value included:

- Professionals who are well-trained and have a good understanding of dementia and the effects it has on people
- Being involved in decisions about care and support
- Always being treated with kindness, dignity and respect
- Being treated as an individual
- Care that is person centred and takes account of the whole person, their likes and dislikes, their spiritual and cultural needs

7.1.3 As noted in section 3 the provision of quality care to people with dementia requires skills over and above basic care skills since *'The symptoms of dementia mean carrying out relatively simple care tasks requires a good understanding of the condition and its effects.'*[102] Hence ensuring that every member of the care workforce has appropriate training and that managers are seen to place a high value on this training, are key components of good quality dementia care that respects individual's dignity and safety.

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[102] All Party Parliamentary Group on Dementia (2009)

7.2 Developing the pathway

7.2.1 The benefits of an integrated dementia care pathway which focuses more on the social care needs of people with dementia and their families based around the communities where they live were discussed in section 3.4. A consultation event took place in East Kent in March 2011 to involve patients in the development of a number of care pathways including dementia. The Kent & Medway Health and Social Care Dementia Commissioning Board have also consulted with a range of stakeholders on the development of a dementia care pathway (post-consultation draft at appendix 10). This outlines a model of care focusing on early intervention measures and integrated services to support people with dementia and their carers, working closely in future with new GP Commissioning bodies (clusters of GP practices who will work together to commission services).

7.2.2 This review has highlighted some of the issues raised by people living with dementia and carers about where the current pathway approach is letting people down. Particular concerns about the ability of domiciliary care to safeguard people at home are expressed in section 3 of this report. Assistive Technology may in some part address this but it is essential that there is a framework in place for risk management which is consistent with current guidance.[103]

7.3 Evidence based service development

7.3.1 There is a commitment from the coalition government to support and drive forward research into dementia in order to improve early diagnosis, treatment and care as well as to gain a better understanding of the different causes of dementia and the discovery of a possible cure. The Department of Health (DH) will invest up to £20 million over the next five years in dementia research through the National Institute for Health Research (NIHR). At the same time DH are encouraging more professionals to enter the field of dementia as well as partnerships between public and private research that ensure the involvement of more people with dementia and their carers. The Medical Research Council (MRC) will also increase its funding for research into neurodegeneration to £150 million over the next four years.

7.3.2 There is an excellent opportunity for dementia service commissioners in health and social care to work closely with academic research bodies in Kent and elsewhere. By doing so, they can ensure that the planning and development of services is informed by evidence from national research. There will also be the opportunity to work jointly on locally based research projects which push boundaries and test innovative ways of improving the lives of people with

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[103] Department of Health (2010)

dementia and carers. KCC's Research and Evaluation team already have links with academic partners all over the country and internationally. Kent is particularly fortunate to have good local links with research partners at the Personal Social Services Research Unit (PSSRU) at Kent University. The Select Committee is in very much in favour of co-operative working on dementia-related research such as that outlined briefly in section 5.5 with regard to Shared Lives Schemes.

7.3.3 Kent also has the benefit of a Dementia Services Development Centre (DSDC) based at Christ Church University in Canterbury which is one of six such centres across the country, serving also the Sussex and Surrey areas. DSDC is 3-way funded by the University, Dementia UK and Avante Care (who have care homes in Kent and SE London).[104] The Centres provide information, training and development and DSDC in Canterbury has been instrumental in the dissemination of established and emerging best practice in quality dementia care. DSDC seek to involve practitioners from all health and social care sectors through a programme of conferences, lectures and workshops involving people living with dementia and carers. A recent lecture series open to professionals and others with an interest has included the following topics designed to explore and disseminate good practice on different aspects of dementia care:

- 'Circle dance as an activity for people with dementia and their carers'
- 'Wandering among dementia sufferers: In search of middle ground '
- 'A portrait of life'
  'Dementia care: GP commissioning and the NHS reforms'
- 'Wander-walking: what can we learn from persons living with dementia?'
- 'Improving quality of life for people with dementia'
- 'Advanced care planning in dementia: a qualitative study to explore people with dementia and carer views'
- 'Life is for singing to'
- 'Exploring the Spiritual Needs of People with Dementia' [105]

The Centre organises and hosts an annual international dementia conference. The second conference, in July this year, was entitled 'Talking about Dementia' and all care and health sectors were well represented. There is also a wider partnership between the Centre and different aspects of the University and knowledge transfer within and outside the organisation takes place for example through a dementia awareness project, Skills for Care, and in close partnership with KCC, the Alzheimer's Society and other voluntary sector organisations.

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[104] Dr Penny Hibberd, Director, Dementia Services Development Centre, South East - Hearing 5th April 2011

[105] Canterbury Christ Church University (2011)

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 development of the dementia care pathway in Kent is informed by evidence and best practice. (See also recommendations 6 and12)

7.4 Dementia Training for Social Care Staff

7.4.1 In 2009 an All Party Parliamentary Group looked at the skills gap and the readiness of the social care workforce to deliver personalised dementia care. They found that “the social care workforce has a very limited knowledge of dementia and is therefore not ready to provide high quality dementia care.” Furthermore, since only a third of people with dementia have a formal diagnosis, there is “inaccurate assessment of workforce training needs.” The Group identified that key barriers to improvement included: the low status of care work; lack of regulation; lack of accreditation and funding for training; the unsuitability of 15 minute home care visits to dementia-care; failing to wipe out poor practice and a lack of training support from specialist mental health services. In carrying out that review, the majority of witnesses felt that more comprehensive dementia care training should be mandatory for social care staff and this view has also been expressed to the KCC Select Committee.

7.4.2 Currently, the only compulsory dementia training for KCC adult social staff is the ‘Introduction to Dementia’ training which is a 1-day basic awareness course facilitated by Dementia UK. KCC also offer Dementia Care – Advanced Skills training which includes for example, ‘Behaviour that Challenges’ and while this is well supported by managers and is part of the Care Workers Competency Framework, it is left to individual workers to request it. Given the issues discussed in Section 3.9 Members believe that KCC adult social care staff whose work frequently brings them into contact with older people as well as those who work with adults with learning disabilities should be required to complete the next level dementia training course as part of their career progression. Non-ringfenced funding for this training is provided by the Department of Health. A list of all the next level dementia-specific training available is given at Appendix 11. Increasingly staff in other KCC directorates may be involved in work which brings them in touch with people living with dementia, for example Libraries and Adult Education staff, who could also benefit from this one day training, free at the point of access.

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.

7.4.3 The InLAWS project (Integrated Local Area Workforce Strategies) was established by Skills for Care and the Association of Directors of Adult Social Services (ADASS) in 2009 to support Directors of Adult Social Services with commissioning a workforce that could meet the challenges of personalising adult social care, including neighbourhood working and the employment of Personal Assistants by people using their Personal Budgets. Of central importance are the skills needed by care workers in domiciliary or residential settings in order that they can provide person-centred care. This aspect of Councils' commissioning strategies applies to the whole social care workforce; not just in-house provision.[106] More recently, a report was published by Skills for Care and Skills for Health, to inform curricula and training courses and to aid workforce development[107].

7.4.4 However, changes to funding for training could affect the quality of training taken up by private and voluntary sector providers of care since, for example, government funding for NVQs (Train to Gain) is no longer available.[108] Furthermore, some companies that have in the past had their own training units have, in the current financial climate, dispensed with them (leading to an increased demand for courses offered by KCC.)

7.4.5 KCC offer subsidised training to the wider workforce in the private and voluntary sector and a number of the courses are dementia-specific. The basic dementia awareness training offered by KCC is accredited by the Quality Credit Framework and is the standard (previously NVQ Level 2), to which all residential and domiciliary staff should be trained. The private sector does not have the same competency framework as KCC staff but the Care Quality Commission requires that all care/enablement workers complete these training units if working in residential or nursing homes or in domiciliary care. Common Induction Standard no. 7 applies to person-centred care and 7.3 relates to:

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[106] Department of Health (2006)
[107] Department of Health (2011)
[108] Sharon Buckingham, Head of Adult Learning Resource Team – written evidence

- recognising the signs of dementia;
- being aware why depression, delirium and age related memory impairment may be mistaken for dementia;
- understanding why early diagnosis of dementia is important and
- knowing who to tell if dementia is suspected.

7.5 Dementia Training for Health Care workers

7.5.1 The Select Committee is not aware of particular plans to ensure that professionals from different disciplines are trained together though this is something that people living with dementia and carers who have given evidence to this review have said would be of benefit. There is already some joint training of nurses and social workers during their first year of training at Christ Church University in Canterbury.

7.5.2 Given that only around a third of people with dementia currently have a diagnosis, good communication between GPs, specialists and hospitals is vital. People involved in the care of a person who has a diagnosis of dementia must be aware of that diagnosis and of any medication relating to that diagnosis. They must also be capable of recognising the signs of dementia and taking appropriate action where there is as yet no formal diagnosis. It goes without saying that all professionals and other staff involved in care should know about dementia, its effect on people's ability to communicate about themselves and their needs, and how to ensure those needs are met.

> ***'People with dementia are estimated to make up half of the total number of people who remain in hospital unnecessarily.'***
> NICE (2009)

> ***"Going into hospital is not enjoyable for people with dementia. Nurses who are specially trained to look after dementia patients are required in every hospital."***
> Former Carer evidence - All Party Parliamentary Group on Dementia (2011)

7.5.3 The Select Committee were told about the damaging effects that a stay in hospital can have on people living with dementia. Services which minimise the need for hospital visits are a priority. However there will be occasions when a stay in hospital cannot be avoided. The Equality Act which came into effect in October 2010 places a duty on public bodies to make reasonable adjustments in order that people with a disability are not discriminated against. Furthermore, service providers “should take reasonable steps to find out whether someone is disabled”. Most face to face care from e.g. a doctor, nurse or Personal Assistant, counts as a service in terms of the Act. Quite apart from practical skills and knowledge about dementia that may be acquired through training, the Select Committee are convinced that the very best qualification for people providing care and support is a kind and compassionate nature and a willingness (and ability) to treat people with dementia with dignity and respect, with an appreciation of their individual spiritual needs, as outlined on the next page.

7.5.4 Dementia liaison services make use of mental health practitioners based in hospitals to act as consultants to hospital staff. A House of Commons Public Accounts Report in 2010 recommended that all acute hospitals should put such services in place for older people to reduce inappropriate admissions and ensure patients are discharged to an appropriate location (often helping them to return home rather than being placed in a care home)[109]. Though the recommendation required an immediate response by all hospitals, services have been rather slow to develop though there are examples in both Leeds and Medway. Liaison Nurses can perform a number of services apart from those in relation to admission and discharge, such as informing hospital staff about patients’ needs.

7.5.5 In Kent, there are six older adult liaison nurses who work with the three district general hospitals in East Kent and in West Kent. However, from the evidence heard during the course of this review, Members believe that there may be a low level of awareness among hospital staff about what to do when a patient with dementia is admitted.

> ***“Last year I had to go into hospital for surgery. Despite my family telling staff of their concerns over my wandering, they said everything would be alright. My daughter offered to stay with me but was refused. A few days after my operation I wanted to speak to my wife …they wouldn’t ring her. I was in a lot of pain and I felt that the staff weren’t listening to me… I left the hospital, no one saw me go. I walked over a mile from the hospital in my pyjamas, carrying 2 catheter bags in the pouring rain… I reached a garage and asked if I could use their phone, but I couldn’t remember my number… From then on my daughter was allowed to stay with me.”***
> Bob Chandler – written evidence

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[109] House of Commons Committee of Public Accounts (2010)

GOOD PRACTICE AND INNOVATION

NHS CHAPLAINCY TEAM – RECOGNISING SPIRITUALITY IN DEMENTIA

In one person spirituality might be defined by faith or the rituals associated with religious practice. For someone else it might be a feeling of wellbeing or wholeness reached for example through the arts or music, from gardening; the enjoyment of nature or the wonderment of a beautiful place or moment. Because it is concerned with the inner person and the essence of all that person is, an understanding of its value is vital to the dignified care and support of people with dementia regardless of the stage of their condition.

The Chaplaincy (ordained and lay people, employed and voluntary) within the NHS Continuing Care team help people with severe dementia and their carers to engage with their spirituality by providing opportunities to respond to music, visual arts, textures and smells, poetry, prose and 'conversation', as well as to worship in whatever faith they may have.

"It comes out in shafts of insight like sunshine through a crack between curtains, illuminating a moment in time. It may be a word of recognition or a particular memory, a foot tapped to a tune, humming, getting up to dance or a wonderful smile."

While we may forget someone's name or what they said to us – if our interaction with them was positive and they treated us with respect, dignity and compassion, our emotional memory of that interaction will outlive our physical memory of it. A better appreciation of everyone's value as a spiritual being can therefore benefit us all. In advanced dementia, where feelings are more tangible than facts, and feelings evoked are more easily related to those of past experiences, making 'now' a good, positive time is vital and can help to connect a person with their own inner resources for wellbeing. Person or family centred care must also take into account a person's spiritual needs and the impact of their emotional history.

(The Select Committee learned of one man whose behaviour had changed and become challenging. Consideration of his life and of his environment showed that a sword hung on the wall was evoking painful wartime memories. When the sword was removed, he became calmer and more peaceful.)

There is also a need, in care homes and other settings, to ensure that each interaction (however brief) with a person with dementia is as positive as it can be. These brief positive moments can provide 'positive navigation points' throughout the day, eliciting feelings of contentment that endure for longer.

What chaplaincy work has demonstrated is that the opportunity to enhance people's wellbeing through an appreciation of their spiritual needs is just as vital, if not moreso, in relation to people in the early stages of dementia as well as their carers.

Sources:
Rev Pam Beckinsale, Chaplain, KMPT – written evidence
Chris Bostock, Chair, Spirituality Special Interest Group, DSDC – written evidence
Dr Graham Stokes, Director of Dementia Care, Bupa Care Homes – Presentation, 7th June, Ashford

7.5.6 The vital role of training for GPs in dementia has been prominent throughout this review. An All-Party Parliamentary Group on Dementia which reported in July this year[110] found similarly that, as discussed in section 3.5, GPs currently lack the confidence and skills to diagnose dementia and have genuine anxiety about making a mistake on a condition that can have such a profound impact on people's lives. However, the Select Committee believes that it is also significant that some GPs know very little about the services and support available locally or of the increased understanding there is of how to live well with dementia. For this reason the Select Committee hopes that GPs will work with their practices and commissioning groups to assist voluntary sector organisations who wish to come into practices to both raise awareness about dementia and raise confidence in services and support available locally, for example the growing network of memory clubs and peer support.

> ***"When I trained, years ago, there was nothing specific about Dementia. Generally, the earlier you try to diagnose Dementia, the more wrong you can be. Other conditions could account for the symptoms you are seeing and using for your diagnosis. You have to be absolutely sure you are right before you tell someone they have Dementia."***
> Dr John Ribchester – Hearing 23rd March 2011

> ***"One elderly lady had been diagnosed as having dementia. In fact I found she was profoundly deaf and no one had spotted it. Another 92 year old lady received a dementia diagnosis after a very brief test entirely formed of memory questions. She did have memory loss – she did not have dementia."***
> Care Worker – personal communication

7.6 Strategy & Implementation

7.6.1 The responsibility for preparing a Kent and Medway work plan in relation to dementia lies with the Dementia Collaborative. This multi agency Kent and Medway group was set up in July 2009 to drive the actions associated with implementation of the 17 objectives of the National Dementia Strategy in Kent. Its membership comprises Local Authority representatives (including 5 elected Members) and representatives from the three Kent and Medway Primary Care Trusts (PCTs) as well as the voluntary sector. Its work is very closely aligned to the Quality, Innovation, Productivity and Prevention (QIPP) process in Kent. The

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[110] All-Party Parliamentary Group on Dementia (2011)

governance structure for the dementia work stream of QIPP is shown in Figure 15 on the next page. One of its key aims was to facilitate “service redesign and reconfiguration to improve pathways and maximise use of available resources and quality of care through multi-disciplinary care models”. Others were:

- Informing the design and Commissioning of services that respond to the findings of the 2009 Dementia Joint Strategic Needs Assessment
- Delivering an integrated best practice dementia care pathway
- Determining a quality framework, which includes clinical standards and protocols across pathways.
- Supporting innovation and the sharing of best practice
- Undertaking audit and research of the approaches and practices adopted to ensure continual improvement and innovative delivery of high quality dementia service.
- Reducing avoidable duplications in assessment, planning and delivery of services
- Seeking improvements in services and the quality of life for people with dementia and their carers.[111]

7.6.2 There have been a number of structural changes in KCC and the Kent PCTs but the work of Collaborative (now under the Chairmanship of Margaret Howard, KCC Director of Learning Disability and Mental Health) is now progressing. The Collaborative has a good foundation of partnership work on which to build, which is better established than in other Local Authority areas[112]. However, it will be important for the Collaborative to establish forums in all parts of Kent to ensure that there is local representation and for it to work closely with any advisory group to the Health and Wellbeing Board which focuses on dementia.

7.6.3 Health and Wellbeing Boards were discussed in Section 2.9. KCC has ‘early implementer status’ as has Dover District Council but KCC as the county authority have a statutory duty to set up a Health and Wellbeing Board and a Shadow HWB is already in place. The HWB will provide a vital link between KCC and the emerging GP consortia in Kent. Dementia is a topic of such crucial and immediate importance requiring joint work by the LA, health organisations, the voluntary sector and wider society that it will provide an ideal topic of focus for the HWB. The Select Committee applauds the choice of Dementia as one of the first issues upon which the Health and Wellbeing Board will focus.

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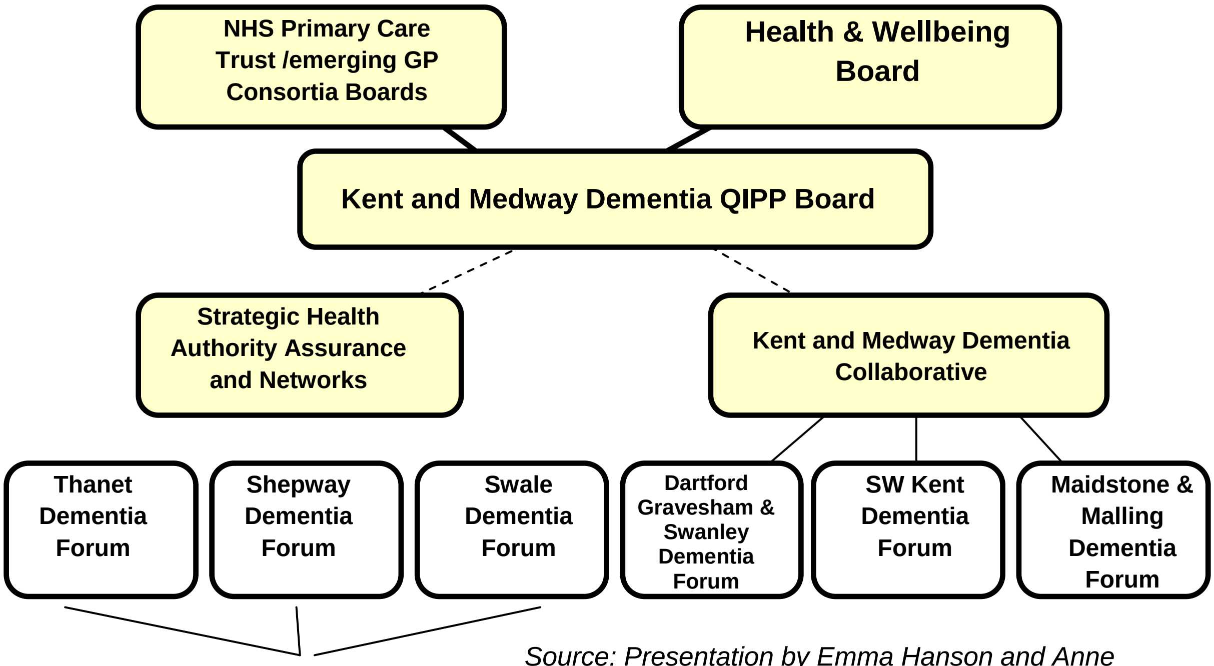
[111] Thomas-Sam, M (2010)

[112] Ian Bainbridge, Deputy Director for Social Care & Local Partnerships, Department of Health South East (Deputy Regional Director of Transforming Adult Social Care Programme Board) – Hearing 9th March 2011

Figure 15: QIPP Governance



East Kent Forums to be established

Source: Presentation by Emma Hanson and Anne Tidmarsh – Hearing 8th April 2011

7.6.4 The Select Committee has learned that the HWB may set up Advisory Groups to inform its work on diverse topics and Members would strongly support there being a group to provide an ongoing focus on development of an improved integrated Dementia Care Pathway. It is worth noting here that the role of the HWB is not to scrutinise, which will remain the role of Health Overview and Scrutiny Committee, but to encourage integrated commissioning.

7.6.5 There is currently a joint social care and health commissioner for dementia in West Kent and although there is separate commissioning in East Kent there is a great deal of co-operative working. Work has been under way in East Kent since 2010 to establish an integrated Health and Social Care commissioning strategy for older people. It acknowledges that at operational level health and social care are often inextricably linked (and for example, in East Kent a number of joint funding agreements are in place between the NHS and KCC including those for integrated care centres at Broadmeadow, Westview and Westbrook House). It also acknowledges that there is ‘a need for a more comprehensive framework for integrated commissioning’ and a move towards a shared vision and strategy, shared targets and shared funding.[113] As noted previously, the older adult’s work of the Kent & Medway Health and Social Care Partnership Trust (KMPT) is not integrated with the Local Authority’s adult social care services.

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[113] Kent County Council (2010)

“I think GPs making their records available to consultants is a long way off, but it would save so much time in appointments if we had access to basic and background information and didn’t have to go and find out all this information each time.”

Dr John Ribchester – Hearing 23rd March 2011

7.6.6 The Select Committee believes that greater integration for example as discussed in section 3.8 with regard to care co-ordination by professionals based with GP practices is essential if people living with dementia are to remain safely at home and receive appropriate care and support. Evidence from one carer, who kept a diary over a period of several months, illustrated the necessity for communication, co-ordination, shared records and joint planning between professionals from different disciplines. NICE Quality Standard 4 says that People with dementia should ‘have an assessment and an ongoing personalised care plan, agreed across health and social care that identifies a named care coordinator and addresses their individual needs.’

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 minimise distress and contribute to cost savings. Continued…**

- **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.**

7.6.7 The Select Committee believes that any strategy or plan put in place to take forward the implementation of a new dementia care pathway in Kent should take account of the differing needs of people with Younger Onset Dementia (YOD) since these needs are not currently being met. One option to ensure that this issue is taken forward would be, as Surrey County Council has done, to develop a separate commissioning strategy for people with YOD. The Surrey Strategy acknowledges the importance of involving younger people with dementia and their carers/families in deciding how best to deliver services differently. Surrey's strategy implementation is however dependent on new investment of £350,000 by the PCT from savings gained by reducing inpatient capacity and by Surrey County Council.[114]

7.6.8 It is difficult for people with YOD to be able to anticipate what services or support they might need later on as the individual effects and impact of their condition become clear. However people with YOD in Kent are now becoming more involved in discussions about services. In some cases this has been via the Peer Support Network set up by the Alzheimer's Society which can be accessed by people with dementia following their diagnosis. The Select Committee has also heard from people who have in the past cared for loved ones with YOD, and are perhaps the most qualified to act as consultants and advocates for people who find themselves among this group.

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[114] Surrey County Council.(2009)

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.**

7.6.9 Local HealthWatch, which will come into force nationally in October 2012, will be the new guise of the Kent Local Involvement Network (Kent LINk) and is the means by which it is intended local residents can play a central role in the delivery of health and social care services in the county. Kent has been granted Pathfinder status by the Government so local people who feel passionate about important health and social care issues, such as services and support for people with dementia and their carers, can become involved and champion these issues. Kent's Pathfinder role means that such champions could have real influence on what happens nationally as well as how HealthWatch develops in the county. Kent LINk, KCC and Kent and Medway Networks (KMN) will be partners in the development of Local HealthWatch, one of the key tasks of which will be to promote the integration of care and health services, a factor which is crucial if dementia services and support are to be improved.

7.7 Co-production and co-design

> ***'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.'***
>
> Boyle, D et al (2010)

7.7.1 Co-production is a term used to describe how public services will be working in order to respond to the dual challenges of maximising resources and improving quality and outcomes. It is particularly relevant to the development of better support for people with long term conditions such as dementia in the future. It represents very well the view expressed by many people living with dementia and carers who participated in this review that ‘they are the experts’ and they are the ones who should be listened to and should be playing a equal role in the design and provision of services to meet increasing needs. Co-production is about providing services and support ‘with instead of ‘to’.

7.7.2 KCC has a long history of consulting with people who are ‘using services’ but this kind of terminology is fast becoming outdated as, with increased personalisation and choice, people have much greater control over the types of support they need and indeed demand. Some of the traditional and often counter-productive barriers that exist between health and social care professionals, the voluntary sector and patients or ‘the public’ will need to be carefully dismantled in order to ensure that all the available resources within communities are mobilised to meet the demographic, financial and other challenges we face.

> ***“Services are still delivered in a top down ‘doing to’ way. We do not use the resources of the individual, family, community.”***
> Simon Bannister, Former Carer – Hearing 29th March 2011

7.7.3 The Select Committee has heard examples which illustrate very well the inability of services as they are currently configured in Kent to meet the needs of people who are living with dementia. People who have needed support in the past and found it lacking often have the clearest view of how things should work in future.

7.7.4 Concepts like the facilitation of peer support groups, which recognise people who might once have been considered as ‘service users’ as ‘assets’ are entirely in keeping with the co-production ethos as is the ‘pump priming’ provided by, for example, Members’ Community Grants which can enable and facilitate people to make their ideas about the way services should be provided, a reality.

> ***“There is also amongst myself and some local young sufferers and carers a desire to try and DO something within their varying capabilities in order to try and contribute. Some guidance and support from the Health Authority would help here.”***
> Keith Oliver – written evidence

7.7.5 Members have spoken to a number of former carers who have expressed a wish to support others in their community who may have recently taken on a caring role and could benefit from empathy, compassion and another person's experience of providing care and support for a person living with dementia. During a consultation event arranged to enable people with an interest in the review topic to give their views, the Select Committee spoke to one former carer who wished to set up the kind of support that she would have liked when caring for her husband. With determination and hard work, that wish became a reality and a group is now meeting on a regular basis, catalysing local community support as outlined below.

GOOD PRACTICE AND INNOVATION

Co-production in Action

Marion is a former carer from East Peckham who has recently put her plans into practice by starting a coffee morning for carers allied to a local day service. Marion cared for her husband until he died and in coming to terms with her own grief, saw an opportunity to help other people caring for a person with dementia.

Excited by the success of the 'launch', an initial brief report of the first coffee morning said that:

- Representatives from local dementia and carers' support organisations attended and provided guidance, pamphlets and brochures
- An Admiral Nurse and trainee attended and spoke to many of those present
- Carers from the nearby day care group called in
- The Parish Clerk and Vice Chairman of the Parish Council attended and provided practical support (including the room)
- The local village Community Officer 'who keeps an eye on the village' called in and will spread the word about the group
- Friends contributed by making tea and coffee
- The Local GP (with whom the new venture was discussed) has said he will refer patients (through 'patient participation') on to the group.

People who came along said they thought the group was a great idea!

Source: Former carer – written evidence

7.7.6 KCC's Social Innovation Lab (SILK) have carried out a Co-production event in Dover which explored various topics including dementia and they are now planning follow up work with GP practices in East Kent that are keen to explore how to provide better community support for people with dementia. This will greatly complement the work of the Select Committee. The Select Committee is very supportive of SILK taking forward any of the recommendations of this review, working with professionals, the voluntary sector, people living with dementia and carers. There may also be an opportunity to involve participants in this review in taking forward some of the recommendations and ideas to which they have contributed.

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.

7.7.7 The final words in this report are those of Bob Chandler, who has younger onset dementia. Bob collaborated on a piece of work[115] to produce a speech that he has now made to hundreds of people on training days and other occasions such as the Kent and Medway NHS and Social Care Partnership Trust Annual General Meeting. Sometimes this can be hard for him, but he is determined to raise awareness about the impact of dementia on younger people and their families and ensure that the experience of other people living with dementia is improved.

"… 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."

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[115] Bob Chandler collaborated on this work with Frances Cook, Community Support Worker, KMPT as part of her dissertation for a Degree in Applied Psychology with Clinical Psychology. She and Bob experimented with fonts and formats as well as different ways of expressing how he felt. Bob's words were shared with the Select Committee by Reinhard Guss, Consultant Clinical Psychologist, Mental Health Services for Older People, Clinical Lead for YOD, KMPT as part of written evidence to the review, with Frances and Bob's consent.

Appendix 1: Glossary

BBA	British Banking Association
BME	Black and Minority Ethnic
CHEI	Cholinesterase Inhibitors (drugs to increase the presence of ‘chemical messengers’ in the brain)
CMHT	Community Mental Health Team
CPA	Care Programme Approach
CQC	Care Quality Commission
Deanery	NHS providers of postgraduate medical and dental training
Elective care	Planned treatment within secondary healthcare services
EPA	Enduring Power of Attorney
ESCA	Effective Shared Care Agreement
HPO	Health Provider Organisation
IMPACT Awards	Awards run by GlaxoSmithKline and The King’s Fund
JNA	Joint Needs Assessment
JSNA	Joint Strategic Needs Assessment
KCC	Kent County Council
KMPT	Kent and Medway NHS and Social Care Partnership Trust (Mental Health Trust)
LPA	Lasting Power of Attorney
MCA	Mental Capacity Act (2005)
MCI	Mild Cognitive Impairment
MMSE	Mini Mental State Examination
MoM	Map of Medicine
NDS	National Dementia Strategy (2009)
NICE	The National Institute for Health and Clinical Excellence
OPG	Office of the Public Guardian
OPMHN	Older People with Mental Health Needs (most often used to denote dementia)
PALS	Patient Advice & Liaison Service
POPPI	Projecting Older People Population Information (Database) http://www.poppi.org.uk/
Primary Care	‘Primary care refers to services provided by GP practices, dental practices, community pharmacies and high street optometrists. Around 90 per cent of people’s

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[116] Department of Health: http://www.dh.gov.uk/en/Healthcare/Primarycare/index.htm

	contact with the NHS is with these services'.'[116]
PSSRU	Personal Social Services Research Unit
QIPP	Quality, Innovation, Productivity and Prevention – NHS framework for the delivery of savings while maintaining or improving services
QOF	Quality Outcomes Framework
REPoD	Rotarians easing the Problem of Dementia
RMN	Registered Mental Nurse
RN	Registered Nurse
Secondary Care	Specialist Care (to which a GP would refer for more in depth tests or diagnosis – e.g. Memory Service). Also referred to as 'Acute' care. Includes hospitals.
'Sectioning'	The Mental Health Act 2007 replaced the Mental Act 1983 but remained largely unchanged on the aspects relevant to dementia. It deals with people who are medically assessed as having a 'mental disorder'. If someone is thought to be at risk to themselves or to others, or if their health is thought to be at risk, they can be detained in hospital ('sectioned') under this act though most people are admitted into hospital on a voluntary basis.
SILK	Social Innovation Lab Kent
Sundowning	Increased disorientation or confusion experienced by some people with Alzheimer's type dementia at the end of the day. Low levels of light can mean that there are fewer visual clues to compensate for sensory impairments.
Third Sector	Charities, voluntary sector, social enterprises – not for profit organisations
WAD	Working Age Dementia (alternative term for Younger Onset Dementia)
YOD	Younger onset dementia (onset under the age of 65)

Appendix 2: Written & Supplementary Evidence and data

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 Chief 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 Clinical 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	
Ingerson, David	Director	Find-me Technologies Pty Ltd
Jarvis, Mrs J	Carer	
Jones, Gillian	Former Carer	
Kanagasooriam, Dr David	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, Dr. Samantha	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 Services Manager	Alzheimer's Society Kent and Medway
Silk, Christie	Assistant Policy 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	
Cloake, David	Head of Emergency Planning	
Critchley, Uta	Emergency Planning Officer	
Davis, Caroline	Policy Manager	
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 Members[117]		
Ayris, Judy (1)		Dementia Outreach Service for Carers, Age UK, Canterbury
Hanson, Emma (1)	Joint Commissioning Manager (Dementia)	Kent County Council
Henderson, Dr Catherine (1&2)	Research Officer	London School of Economics and PSSRU University of Kent
Kanagasooriam, Dr David (1)	GP	Whitstable Medical Practice
Locke, Christine (1&2)		Diversity House
Savitch, Nada (1&2)	Director	Innovations in Dementia CIC
Seabrooke, Dr Viniti (2)	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

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

Appendix 3: 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

Panel Discussion (Crisis and Emergency – Prevention and Response theme):

- Linda Caldwell, Older Person Commissioning Manager, NHS Eastern and Coastal Kent
- David Ivatt, Operations Manager, Kent Search and Rescue
- Michael Smith, Team Leader - Vulnerable People Team, Kent Fire & Rescue
- Jamie Waldie, Dementia Support Worker, Crossroads Care

8th April 2011

Interviews:

- Justine Leonard, Service Line Director for Older Adult and Specialist Services, Kent and Medway NHS and Social Care Partnership Trust (KMPT)

- Interview with Anne Tidmarsh, Director of Commissioning and Provision (and County-wide QIPP Lead for Dementia), and Emma Hanson, Joint Commissioning Manager, Dementia

- Hazel Price, Programme Manager, Kent Whole Systems Demonstrator Project and Fay Scannell, Telecare and Telehealth Project Officer

Appendix 4: Training and visits

26th January 2011
Members' Briefing/Training - Alzheimer's Society, Maidstone
Contacts: Teresa Harrison-Best, Tina Stirling (Alzheimer's Society); Linda Caldwell, NHS Eastern and Coastal Kent; Emma Hanson, Jane Barnes, KCC

2nd February 2011
Hazell Neville Centre, Age UK, Herne Bay (day centre)
Main contact: Julie Sayers

4th February 2011
Westbrook House, Margate (Integrated Care Centre)
Main contact: Angela Locke

7th February 2011
Alzheimer's and Dementia Support Services, Northfleet (Voluntary Sector)
Main contact: Dr Viniti Seabrooke

10th February 2011
Priory Mews, Dartford (BUPA Nursing Home)
Main contact: Sharon Crouch

11th February 2011
Dementia Café, St Stephens, Canterbury (Alzheimer's Society)
Main contact: Megan Jones

18th February 2011
East Kent Independent Dementia Support (EKIDS) – Launch, Marine Hotel, Tankerton
Main contact: Janet Britt

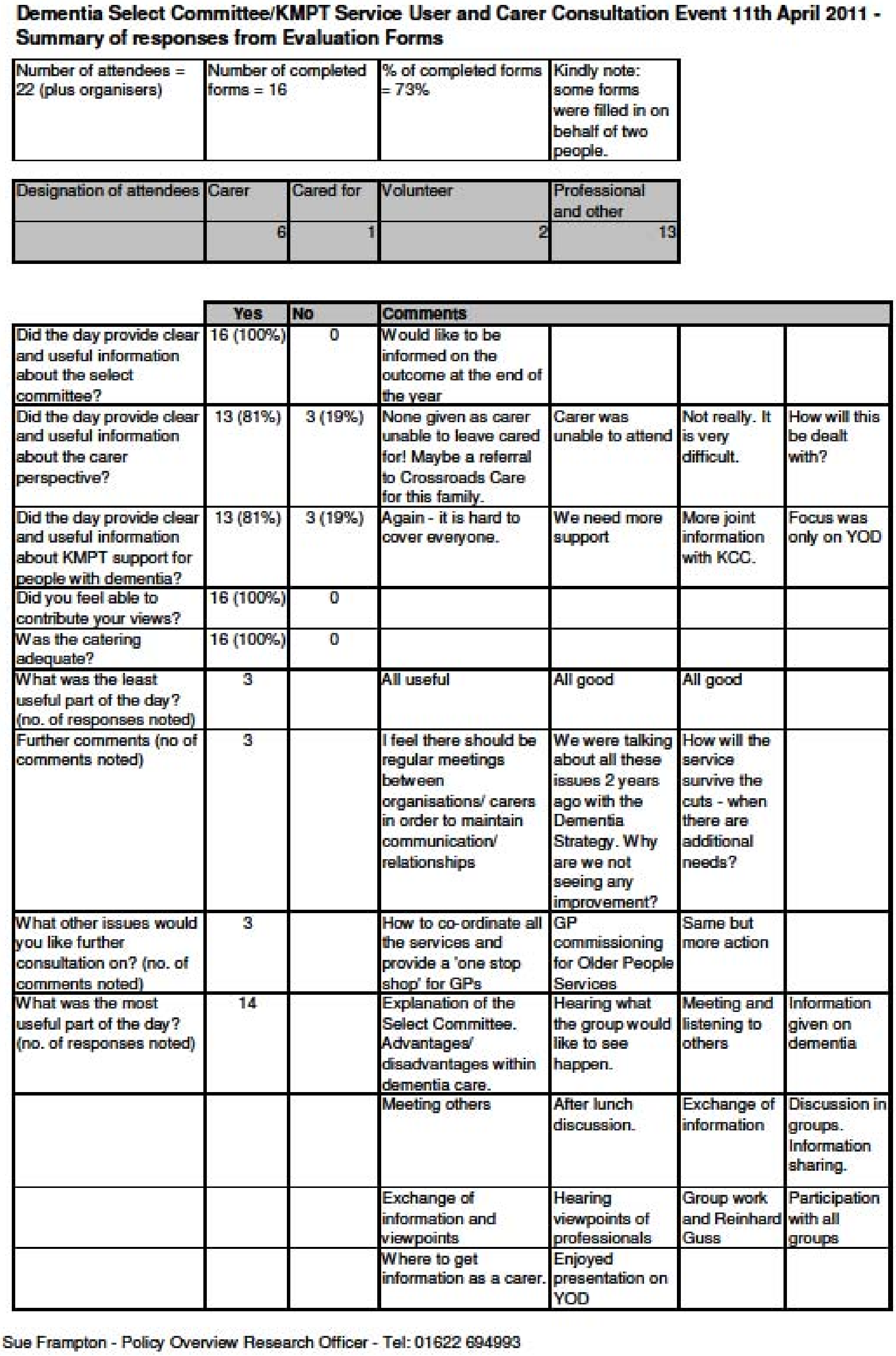
22nd February 2011
Peer Support Group, Linton, Maidstone (Alzheimer's Society)
Main contact: Ellie Potier

23rd February 2011
Day Services, Park Lodge, Tudeley (Alzheimer's Society)
Main contact: Tina Stirling (Informal meeting with Henry – Carer and Ursula - Carer)

28th February 2011
Dementia Café, Hollybush Day Centre, Sevenoaks (Alzheimer's Society)
Megan Jones

8th March 2011
Memory Café/club, St Christopher's Church, Newington, Ramsgate (EKIDS)
Janet Britt

Appendix 5: Consultations undertaken as part of the select committee review - feedback summaries for events on 11th and 15th April 2011[118]



Dementia Select Committee/KMPT Service User and Carer Consultation Event 11th April 2011 - Summary of responses from Evaluation Forms

Number of attendees = 22 (plus organisers)	Number of completed forms = 16	% of completed forms = 73%	Kindly note: some forms were filled in on behalf of two people.

Designation of attendees	Carer	Cared for	Volunteer	Professional and other
	6	1	2	13

	Yes	No	Comments			
Did the day provide clear and useful information about the select committee?	16 (100%)	0	Would like to be informed on the outcome at the end of the year			
Did the day provide clear and useful information about the carer perspective?	13 (81%)	3 (19%)	None given as carer unable to leave cared for! Maybe a referral to Crossroads Care for this family.	Carer was unable to attend	Not really. It is very difficult.	How will this be dealt with?
Did the day provide clear and useful information about KMPT support for people with dementia?	13 (81%)	3 (19%)	Again - it is hard to cover everyone.	We need more support	More joint information with KCC.	Focus was only on YOD
Did you feel able to contribute your views?	16 (100%)	0				
Was the catering adequate?	16 (100%)	0				
What was the least useful part of the day? (no. of responses noted)	3		All useful	All good	All good	
Further comments (no of comments noted)	3		I feel there should be regular meetings between organisations/ carers in order to maintain communication/ relationships	We were talking about all these issues 2 years ago with the Dementia Strategy. Why are we not seeing any improvement?	How will the service survive the cuts - when there are additional needs?	
What other issues would you like further consultation on? (no. of comments noted)	3		How to co-ordinate all the services and provide a 'one stop shop' for GPs	GP commissioning for Older People Services	Same but more action	
What was the most useful part of the day? (no. of responses noted)	14		Explanation of the Select Committee. Advantages/ disadvantages within dementia care.	Hearing what the group would like to see happen.	Meeting and listening to others	Information given on dementia
			Meeting others	After lunch discussion.	Exchange of information	Discussion in groups. Information sharing.
			Exchange of information and viewpoints	Hearing viewpoints of professionals	Group work and Reinhard Guss	Participation with all groups
			Where to get information as a carer.	Enjoyed presentation on YOD		

Sue Frampton - Policy Overview Research Officer - Tel: 01622 694993

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[118] Please note that consultations were arranged in collaboration with Nick Dent, PALS Manager (East) KMPT. The 11th April event was held at St Martin's Hospital ,Canterbury (presentation by Reinhard Guss); the 15th April event was held at Invicta House, Maidstone (presentations by Dr Ananth Puranik and Tom Coppins).

Dementia Select Committee/KMPT Service User and Carer Consultation Event 15th April 2011 - Summary of responses from Evaluation Forms

Number of attendees = 19 (plus organisers)	Number of completed forms = 12		% of completed forms = 63%	Kindly note: some forms were filled in on behalf of two or more people.

Designation of attendees	Carer/ex-carer	Cared for	Professional and other
	9	3	7

	Yes	No	Not answered	Comments				
Did the day provide clear and useful information about the select committee?	12 (100%)	0						
Did the day provide clear and useful information about the carer perspective?	10 (83%)	0	2 (17%)	Yes but as a carer organisation representative	(Yes) but need more information on services as the disease progresses.			
Did the day provide clear and useful information about KMPT support for people with dementia?	11 (92%)	0	1 (8%)	Very useful	(Yes) but I was surprised that it actually existed!			
Did you feel able to contribute your views?	12 (100%)	0		(Yes) but not enough time	Wasn't quite enough time for a long discussion			
Was the catering adequate?	11 (92%)	0	1(8%)					
What was the least useful part of the day? (no. of responses noted)	5			Some of the reports	All day was well organised	All useful	None	There wasn't one
Further comments (no of comments noted)	5			Well worth while	Good selection of people attended	Should have been a whole day event - more discussion time needed. Will there be further events?	Why are we closing resources when dementia is on the increase?	I would like to think that as a result of this forum KCC would be proactive about advice after diagnosis
What other issues would you like further consultation on? (no. of comments noted)	3			Larger event - more people wanted to come but were told it was full. Less staff and more carers/pwd - some tables had two facilitators - this meant less places available for service users.	Home help	There should be regular consultations on this subject to inform services.		
What was the most useful part of the day? (no. of responses noted)	10			An excellently planned and useful day - can we know of and attend follow ups as and when.	Feedback session on gaps in service and positives	Q&A	The feedback from group work	After speech discussions
				The joint sharing of information	Group comments	All information	Putting my views across to Dr Puranik and Trudy Dean	Good discussion of the issues.

Sue Frampton - Policy Overview Research Officer - Tel: 01622 694993

Appendix 6: 17 Objectives of the National Dementia Strategy 2009

There are 17 objectives, which focus on four key areas for improving the quality of life for people with dementia and carers raising awareness and understanding, early diagnosis and support, living well with dementia and making the change (implementing the Strategy).

Objective 1: Public information campaign
A significant national awareness campaign is proposed that focuses on explaining what dementia is, the importance of diagnosis, help that is available, reducing stigma and promoting prevention. It suggests that local complementary campaigns should also be run.

Objective 2: Good quality early diagnosis and intervention
The Strategy proposes local commissioning of a good quality memory service which can provide early specialist diagnosis. Memory services might most appropriately be based in a community setting.

Objective 3: Good quality information
Good quality information should be available for people with dementia and their carers. A one year review of existing information is proposed, followed by the development and distribution of a set of good quality information on dementia and services. Information on local service provision should be tailored to that area.

Objective 4: A dementia adviser
Following diagnosis, all people with dementia should have access to a dementia adviser who can act as a point of contact for information and signposting to other services. The focus of work would be to help people with dementia to navigate the health and social care system. The DH proposes a series of demonstrator sites to examine which dementia adviser model works best and to evaluate impact on quality of life.

Objective 5: Peer support and learning networks
The Strategy proposes the development of peer support networks such as support groups and dementia cafes for people with dementia and their carers. The intention is to provide practical and emotional support, reduce social isolation and promote self help. The Strategy proposes a demonstration and evaluation programme to evaluate peer support activity.

Objective 6: Improved community personal support services
It is recommended that an appropriate range of services needs to be put in place to support people with dementia and their carers in their own homes, with a range of options available from early intervention to specialist services. A dedicated programme will establish an evidence base on which specialist services are effective.

Objective 7: Implementing the Carers' Strategy

It is recommended that unpaid carers need to be given access to a wide range of support to help them in caring for people with dementia. In particular work on the Carers' Strategy should focus on people with dementia and ensure that effective assessment, support and short breaks (respite) packages are available.

Objective 8: Improving care in hospitals

The Strategy proposes three key changes to dementia care practice in hospitals.

- Identifying a senior clinician who will be responsible for quality improvement in dementia.
- Developing an explicit agreed care pathway for people with dementia in hospitals, explaining how people with dementia will be cared for, by whom and in what way.
- The development of specialist older people's mental health liaison teams that can support staff throughout hospitals to care for people with dementia.

Objective 9: Improving intermediate care

Intermediate care services support people who have had a serious health incident. They allow these people to remain in their own homes without requiring hospital care, or to recover from a stay in hospital. Many intermediate care services currently wrongly exclude people with dementia. The DH will be issuing new guidance on intermediate care in 2009, with explicit reference to people with dementia.

Objective 10: Housing and telecare

People with dementia should be included in locally developed housing options and should be able to take advantage of assistive technology and telecare.

Objective 11: Improving care in care homes

The Strategy recommends a number of steps be taken to improve quality of care in care homes:

- A named senior member of staff should take the lead for improving quality of dementia care in every home.
- This senior staff member should develop a local strategy for management and care of people with dementia.
- Anti-psychotic medication should only be used when appropriate.
- Specialist in-reach services should be commissioned to provide specialist advice and guidance on improving care.

Other in-reach services such as primary care, pharmacy, dentistry should be available.

- Specialist guidance for care staff on best practice in dementia care should be provided.

Objective 12: Improving end of life care
Palliative care at the end of life needs to be improved. This objective suggests the involvement of people with dementia in planning end of life care in keeping with the principles of the Mental Capacity Act. Local work on the End of Life Care Strategy needs to consider dementia. The Strategy proposes a programme of demonstration, piloting and evaluation projects to assist development of end of life care in dementia.

Objective 13: Workforce competencies, development and training
All health and social care staff involved in the care of people with dementia should have the skills to provide the best quality care to people with dementia and their families. The DH will work with representatives of all bodies involved in professional, vocational and continuing professional development to agree the core competencies required in dementia care. Those bodies will then consider how to adapt their curricula. Commissioners of services should specify dementia training as a requirement for service providers.

Objective 14: Joint local commissioning and World Class Commissioning
The Strategy recommends that local commissioning and planning mechanisms need to be established to determine how best to meet the needs of people with dementia and their carers. These should be informed by the Dementia World Class Commissioning guidance developed to support the Dementia Strategy. The guidance on World Class Commissioning in Dementia is one of only five areas where guidance has been developed. This emphasises the importance of progress in relation to dementia and shows recognition of the challenges that commissioners face. This also complements the identification of dementia as a priority in the 2009/10 NHS Operating Framework, and the call for Strategy Health Authorities to monitor it. Primary Care Trusts (PCTs) and local authorities will be expected to work together to consider how they can improve dementia services.

Objective 15: Improved registration and inspection of care homes
Registration and inspection regimes should reflect the need for good quality dementia care. The Strategy includes a statement agreed with the Care Quality Commission setting out how they expect to regulate and inspect care homes.

Objective 16: Dementia research
The DH will work with the Medical Research Council to convene a summit of research funders and scientists interested in dementia research. This will be used to generate a plan for the development of dementia research in the UK.

Objective 17: National and local support for implementation
The DH will provide regional support to commissioners and providers implementing the Strategy to ensure progress.

Appendix 7: NICE Dementia Quality Standard

1. People with dementia receive care from staff appropriately trained in dementia care.
2. People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.
3. People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
4. People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care that identifies a named care coordinator and addresses their individual needs.
5. People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of: advance statements, advance decisions to refuse treatment, Lasting Power of Attorney, Preferred Priorities of Care.
6. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.
7. People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.
8. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people´s mental health.
9. People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.
10. Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

The full Standard can be found online at:
http://www.nice.org.uk/media/7EF/3F/DementiaQualityStandard.pdf

Appendix 8: Admiral Nurses in Kent

East Kent

Ashford
Kent and Medway NHS and Social Care Partnership Trust
William Harvey Hospital
Kennington Road
Willsborough
Ashford
Kent
TN24 0LZ
Tel: 01233 616 185

Canterbury
Kent and Medway NHS and Social Care Partnership Trust
The Flats
St Martin's Hospital
Littlebourne Road
Canterbury
Kent
CT1 1TD
Tel: 01227 812083

Dementia Services Development Centre
Canterbury Christ Church University
Becket East S24
North Holmes Road
Canterbury
Kent CT1 1QU
Tel: 01227 782 602

Dover and Deal
Kent and Medway NHS and Social Care Partnership Trust
Coleman House
Brookfield Avenue
Dover
Kent
CT16 2AH
Tel: 01304 216 624

Shepway (Folkestone, Folkestone Villages, Romney Marsh)
Kent and Medway NHS Social Care Partnership Trust
Broadmeadow Registered Care Centre
Park Farm Road
Folkestone
Kent
CT19 5DN
Tel: 01303 852 660

Swale
Kent and Medway NHS and Social Care Partnership Trust
Southlands Unit
Rook Lane
Bobbing
Sittingbourne
Kent
ME9 8DZ
Tel: 01795 845019

Thanet
Kent and Medway NHS and Social Care Partnership Trust
The Beacon
Manston Road
Ramsgateth
Kent
CT12 6NT
Tel: 01843 854 215

West Kent Admiral Nurses

Dartford, Gravesham and Swanley
Kent and Medway NHS Social Care Partnership Trust
Jasmine Centre
Darenth Wood Road
Dartford
Kent
DA2 8DA
Tel: 01322 421 289

Maidstone
Kent and Medway NHS and Social Care Partnership Trust
Priority House
Hermitage Lane
Maidstone
Kent
ME16 9PH
Tel: 01622 725 000

Sevenoaks, Tonbridge & Tunbridge Wells

Sevenoaks & Tonbridge
Kent and Medway NHS and Social Care Partnership Trust
Darent House
Sevenoaks Hospital
Hospital Road
Sevenoaks
Kent
TN13 3PG

Tel: 01732 228 246

Tunbridge Wells
Kent and Medway NHS and Social Care Partnership Trust
Highlands House
12 Calverly Park Gardens
Tunbridge Wells
Kent
TN1 2JN
Tel: 01892 709 200

Medway
Kent and Medway NHS and Social Care Partnership Trust
Elizabeth House
Holding Street
Rainham
Kent
ME8 7JP
Tel: 01634 382 091

Appendix 9: 10 Signs of Alzheimer's

(shown here with kind permission of the American Alzheimer's Association. Online at: http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp)

1

Memory loss that disrupts daily life

One of the most common signs of Alzheimer's is memory loss, especially forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; relying on memory aides (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own.

What's a typical age-related change? Sometimes forgetting names or appointments, but remembering them later.

2

Challenges in planning or solving problems

Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.

What's a typical age-related change? Making occasional errors when balancing a checkbook.

3

Difficulty completing familiar tasks at home, at work or at leisure

People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game.

What's a typical age-related change? Occasionally needing help to use the settings on a microwave or to record a television show.

4

Confusion with time or place

People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.

What's a typical age-related change? Getting confused about the day of the week but figuring it out later.

5

Trouble understanding visual images and spatial relationships

For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not realize they are the person in the mirror.

What's a typical age-related change? Vision changes related to cataracts.

6

New problems with words in speaking or writing

People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a "watch" a "hand-clock").

What's a typical age-related change? Sometimes having trouble finding the right word.

7

Misplacing things and losing the ability to retrace steps

A person with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.

What's a typical age-related change? Misplacing things from time to time, such as a pair of glasses or the remote control.

8

Decreased or poor judgment

People with Alzheimer's may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.

What's a typical age-related change? Making a bad decision once in a while.

9

Withdrawal from work or social activities

A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced.

What's a typical age-related change? Sometimes feeling weary of work, family and social obligations.

10

Changes in mood and personality

The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone.

What's a typical age-related change? Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

Appendix 10: Dementia Care Pathway (page 1 – post consultation draft)

Kent and Medway Integrated Dementia Care Pathway	**Step one** Person or carer, seeking information or wondering what's happening. Everyday life harder, beginning to be worried, some role changes	**Step two** Seeking access to professional advice or left alone with fears and worries. Really worried about what's happening, confused over possible causes.	**Step three** Going through an assessment or left in uncertainty. Having various tests to clarify what is happening may or may not want to know results.
Prevention Public awareness campaign raising awareness about dementia. To include message ***What's good for your heart is good for you head*** In order to promote good cardio vascular health and wherever possible prevent incidents of vascular dementia **National and Local campaigns to raise awareness** **Ensure vulnerable groups receive adequate physical care** **Encourage preventative measures:** ***Stop smoking*** ***Eat healthily*** ***Drink alcohol sensibly*** ***Exercise more*** ***Regular health checks*** NDS1	**Identification** Campaigns to reduce stigma attached to dementiia - to encourage people to self identify and come forward for assessment and support. Public and professional awareness of dementia raised to dispel the myth that dementia is a natural part of ageing and 'nothing can be done'. Ensure professionals can identify possible signs of Dementia and know where and how to refer people for memory assessment. Use of standard screening tools to identify symptoms that warrant referral to memory services. All professionals aware of the process for assessment and diagnosis. NDS1	**Assessment and Diagnosis** Appropriate baseline tests will be undertaken to exclude other causes of cognitive impairment including medication review. Ensure that there is a shared understanding of what these tests are and who will undertake them. Recognition of the difference between dementia and delirium There will be an agreed protocol for who makes the diagnosis and when. Where an individual does not want to receive a dignosis, they (and their carers) can access appropriate services based on need, not diagnosis. There will be an agreed timely process for ongoing assessment and review. There will be a specific assessment pathway for people with learning disabilities who go on to devlop dementia. NDS 2,3 4 NICE QS2	**Early Intervention and Treatment.** Anti dementia drugs will be prescribed, where appropriate, in accordance with NICE guidelines. Post diagnostic support and information is available to the person with dementia and their carer. This includes: • Psychological support. • Benefits advice. • Advance and end of life planning. • Information on support services. • Carers assessment. The person with dementia to be added to Quality and Outcomes Framework (QOF) register which will trigger the annual review which should include physical examination, cognitive assessment, medication review and review of social situation and needs of carers/family. Where appropriate, carer to be added to the carer's register. Referal to advisory services and peer support networks NDS 2,3 4 NICE QS 3, 4 & 5
Well Trained Staff NICE QS1 NDS13			
Support, Advice and Information NDS 3			
Assessment, Re-Assessment and Review			

NDS = National Dementia Strategy Objective
NICE QS = NICE Dementia Quality Standard

Appendix 10: Dementia Care Pathway (page 2 – post consultation draft)

<table>
<tr>
<td>Step four
May be receiving some help may still be refusing to acknowledge any problem. Trying to stay independent and not lose memory. Trying to cope and to stay in own home. Likely to have been diagnosed as having dementia and may or may not have been told.</td>
<td>Step five
Service response from somewhere necessary, which could be temporary. Deteriorating situation diminished memory struggling, abilities lost, accidents may be happening may also be physically unwell. Carer's strained to the limit, could be beginning to seem unsustainable to stay at home – capacity to consent to help is fading.</td>
<td>Step six
Somewhere else to live is necessary which could be temporary
May be a crisis precipitates leaving own home, could be a fall or having an acute physical illness or it could be that behaviour has progressively become too challenging for carers, or neighbours, to cope. Person is anxious and stressed and very confused.</td>
<td>Step seven
Intensive care to survive and not hurt self or others is needed. There is a complex interation of different needs deteriorated mental state, that may include grossly disturbed and confused behaviour, little and/or no apparent connection with people and things, knowledge of basic skills lost.</td>
<td>Step eight
Support to die
The person has stopped behaving in a disturbed way but cannot perform any basic living skills. Will have associated physical health problems overlaid on the dementia.</td>
</tr>
<tr>
<td colspan="4">Living Well with Dementia
Dementia to be recognised as a long term condition and people with dementia and their carers will have access to the same type and level of service as people living with any other long term condition, a person's physical care e.g. eating; continence will form part of their assessments and reviews. Care and support will be person centred and personalised offering choice and control about the level and type of care provided. Where appropriate, personal budgets will be in place to enable individuals to have choice about service delivery.

People will have access to a range of community services which will include: peer support, dementia cafes, domiciliary care, carer's support, day services, flexible shortbreak support -both in the home and away from the home. People with dementia will access a range of assistive technology to support them at home.

Mental Capacity Act must be appropriately to enable people with dementia to have maximum choice and control about the decisions that effect life to manage risk and ensure that decision are always made3 with the person best interest in mind. Including support to consider future legal needs such as lastingpower of attorney.

Crisis services to be available 24/7 to help maintain people in their own homes and avoid unnecessary hospital admissions. Intermediate care services will also be available in the community and there will also be access to intermediate care beds for both physical and mental health issues to avoid where possible admissions to acute hospital care. Out-of-hours services record their visits and findings in the patients' notes and feedback to GP's when necessary.

If a person with dementia requires admission to an acute hospital, care will be delivered by staff who have the knowledge and skills to deliver good qualtiy care for people with demenria. Assessment and staff support will also be available from mental health professionals as part of a liaison psychiatry service. Hosptial dischare process will vaule the input of carers and ensure that their opinions and wishes are considered as part of discharge process.

Good quality mental health inpatient care will provide assessment and treatment only when this cannot be delivered in a community setting.

When a person can no longer be cared for in their own home this will be provided by a range of good quality care homes. If placed in a care home, the individual will have an anticipatory care plan which will provide information to the care home staff about how they manage changes in need and how they access additional support if required. Care homes will also be supported by a range of proactive inreach services which will support staff to meet residents needs and help to avoid unnecessary hospital admissions. Care homes will have the appropriate skills and training to deliver good quality care. Processes will be in place to support care homes to ensure these skills are in place
NDS 5,6,7 8, 9 ,11 and 12
NICE QS 4, 6, 7 , 8 &10</td>
<td>End of Life Care
Dementia will be recognised as a terminal illness and will be included in all local end of life pathways and people with dementia will have equitable access to services designed to support end of life care. The end of life anticipatory care planning to include choices about n end of life care and DNA CPR.

Where a person with dementia has an advance care plan in place, end of life wishes will be complied with.

Cultural and spiritual differences/preferences will be identified and implemented.

Carers and families will be involved with all care decisions.

Where possible, people with dementia will not be moved from their usual place of residence in their last days of life.
NDS13
NICE QS 9</td>
</tr>
<tr><td colspan="5">Well Trained Staff NICE QS1 NDS13</td></tr>
<tr><td colspan="5">Support, Advice and Information NDS 3</td></tr>
<tr><td colspan="5">Assessment, Re-Assessment and Review</td></tr>
</table>

Appendix 11: Dementia Training provided for KCC staff by Learning & Resources Team

(facilitated by trainers from Dementia UK)

DEMENTIA AWARENESS - Target Group: All Adult Social Care staff in Families and Social Care Directorate

Course Aim: To provide all staff with the basic knowledge and skills to provide person centred care to people with dementia. Participants will be introduced to the Jackie Pool Ltd learning materials and workbook accredited by the Qualification Credit Framework.

At the end of the course learners will be able to:

- Describe the ageing process and explain how it differs from dementia
- Identify the main features of dementia and the three main types of dementia
- Explain the principles of person-centred care work with people with dementia
- Demonstrate the principles of good communication with people with dementia

DEMENTIA CARE - ADVANCED SKILLS - Target group: Senior Team Leaders and Team Leaders in Dementia Care Units, Staff in Assessment and Enablement and Co-ordination Teams, Kent Enablement at Home Service

Course Aim*:* To provide staff who already have dementia awareness knowledge or who influence care practice with more in-depth knowledge of dementia and explore key concepts relating to the care of people with dementia

Learning Outcomes:

- Review existing knowledge of dementia and person-centred care work Describe the concepts of person-centred care, including well-being and ill-being, personal enhancers and personal detractors, occupation and enablement
- Use well-being and ill-being profiles and review care planning
- Identify and practice effective communication skills for working with people with dementia
- Understand behaviour and manage behaviour that challenges
- Explore relationships between family and care staff

DEMENTIA: BEHAVIOUR THAT CHALLENGES - Target Group: Team Leaders and Careworkers from Older People Provision Services

Course Aim: To consider the changes in behaviour that may happen as a result of dementia, the factors that may contribute to behaviour that 'challenges' and how care-workers can develop strategies for avoiding and/or managing difficult situations.

Learning Outcomes:

- Define what may be behaviour that challenges
- Be aware of the factors that may contribute to behaviour that challenges
- Recognise when behaviour that challenges might occur

- Outline different ways in which behaviour that challenges can be interpreted
- Recognise the impact of our own behaviour on an individual with dementia
- Identify ways of avoiding difficult situations

DEMENTIA: ACTIVITY GROUPS FOR PEOPLE WITH DEMENTIA - Target Group: Team Leaders and Careworkers from Older People Provision Services

Course Aim: To provide staff with an understanding of the principles and best practice in activity work with people with dementia. The course will introduce the PAL instrument and how it can be used to review care planning.

At the end of the course learners will be able to:

- Plan an individual or group activity
- Develop an activity profile for clients that reflects a person's life history, interests and how dementia affects them
- Explore strategies to encourage people to participate who might initially be reluctant or disinterested
- Consider good practice principles in activity work
- Use the PAL instrument and review care planning

LEARNING DISABILITY AND DEMENTIA - **Target group:** All staff in Learning Disability Provision, and staff in Learning Disability Integrated Teams. Team Leaders in Day Centres for older persons

Course Aim: To increase the confidence & skills for those working with clients with a dual diagnosis of learning disability & dementia

Learning Objectives:

- At the end of the course learners will be able to:
- Understand the early signs and symptoms of Dementia
- Use an assessment checklist, to integrate into your current care planning system in order to monitor any changes in a person with a learning disability who is over 50.
- Identify and practice the particular skills needed when working with a person who has dementia and in particular where these might be similar or different to existing approaches to clients with a learning disability
- Better understand the behaviour of a person with a dementia where it is challenging to you or others, and to identify problem-solving strategies.
- Explain and talk openly about dementia to people with a learning disability and the relative or carer of the person, and to offer appropriate support

DEMENTIA: END OF LIFE CARE - **Target group: Staff in Assessment and Enablement and Co-ordination teams, Kent Enablement at Home staff**

Course Aim: To help respond to the ongoing experience of loss faced by people with dementia, their families and themselves to create a therapeutic environment throughout the progression of the illness and at the end of life.

Learning Outcomes:

- Explain the key principles and goals of the Gold Standards Framework, the Liverpool Care Pathway, the NHS National End of Life Care Programme and Objective 12 of the National Dementia Strategy.
- Consider the importance of open communication about end of life and the implications of advance decisions, lasting powers of attorney and the mental capacity act.
- Describe the difference losses faced by a person with dementia and their carers as the illness progresses.
- Explore how they would support a family and each other when caring for a person at the end of life.
- Demonstrate an understanding of communicating therapeutically when working with people who are stressed or bereaved.

References

All Party Parliamentary Group on Dementia (2009) Prepared to Care: Challenging the Dementia Skills Gap. [Online] London: House of Commons. Available from: http://www.nationalcareforum.org.uk/content/APPG%20Report%20PDF%20version.pdf (Accessed September 2011)

All Party Parliamentary Group on Dementia (2011) The £20 billion question: An inquiry into improving lives through cost-effective dementia services [Online] London: House of Commons Available from: http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1207 [Accessed September 2011)

All Party Parliamentary Group on Dementia (2011) 2011 inquiry: Written anonymised evidence from people with dementia and carers (Response 14) [Online] London: House of Commons. Available from: http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1062 [Accessed September 2011]

All Party Parliamentary Group on Dementia (2011) 2011 inquiry: Written anonymised evidence from people with dementia and carers (Response 106) [Online] London: House of Commons. Available from: http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1062 [Accessed September 2011]

All Party Parliamentary Group on Dementia (2011) 2011 inquiry: Written anonymised evidence from people with dementia and carers (Response 117) [Online] Available from: http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1062 [Accessed September 2011]

Alzheimer's Research Trust (2010) Dementia 2010: The economic burden of dementia and associated research funding in the United Kingdom. [Online] University of Oxford. Available from: http://www.herc.ox.ac.uk/downloads/dementiafullreport [Accessed September 2011]

Alzheimer's Society (2010) Factsheet 515: Dementia and Children or Young People [Online] London: Alzheimer's Society. Available from: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=108 [Accessed September 2011]

Alzheimer's Society (2010) Factsheet 430: Learning Disabilities and Dementia [Online] London: Alzheimer's Society. Available from: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=103 [Accessed September 2011]

Alzheimer's Society (2011) Factsheet 400: What is Dementia? [Online] London: Alzheimer's Society. Available from: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=106 [Accessed September 2011]

Audit Commission (2000) Forget Me Not – mental health services for older people [Online] London: Audit Commission. Available from: http://www.audit-commission.gov.uk/SiteCollectionDocuments/AuditCommissionReports/NationalStudies/ForgetMeNot.pdf [Accessed September 2011]

Bamford, S. International Longevity Centre - UK and Pfizer (2010)

A problem shared is a problem halved? Dementia: learning opportunities from Europe. A policy brief. London: ILC-UK

Banerjee, S. (2009) The Use of Antipsychotic Medication for People with Dementia: time for action. [Online] London: DH. Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_108302.pdf (Accessed September 2011)

Boyle, D et al (2010) Right Here, Right Now: Taking co-production into the mainstream. p6 [Online] London: NESTA and nef. Available from: http://www.nesta.org.uk/library/documents/coproduction_right_here_right_now.pdf [Accessed September 2011]

Brawley, E. (1997). Designing for Alzheimer's disease: Strategies for better care environments. New York: John Wiley and Sons.

Canterbury Christ Church University (2011) DSDC Events [Online] Available from:http://www.canterbury.ac.uk/health/dementia-services-dev-centre/Events.aspx [Accessed September 2011]

Care Quality Commission [2011] Essential standards of quality and safety [online] Available from: http://www.cqc.org.uk/usingcareservices/essentialstandardsofqualityandsafety.cfm [Accessed September 2011]

Centre for Public Scrutiny (2010) Walk a mile in my shoes - Scrutiny of dignity and respect for individuals in health and social care services: a guide. [Online] London: CfPS. Available from http://www.cfps.org.uk/what-we-do/publications/cfps-health/?id=113 [Accessed September 2011]

Challis, D. et al (2010) Community Support Services for People with Dementia: The relative costs and benefits of specialist and generic domiciliary care services [Online] PSSRU Manchester. Available from: http://www.medicine.manchester.ac.uk/pssru/PSSRUInformation/ExpertBriefingCommunitySupportforPeoplewithDementiacompleteFINAL.pdf [Accessed September 2011]

Darzi Review (2008) High quality care for all: NHS next stage review final report [Online] London: Department of Health. Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_085828.pdf [Accessed September 2011]

Dementia Advocacy Network (2011) The Right to Advocacy [Online] Available from: http://dan.advocacyplus.org.uk/pages/supporting-people-with-dementia.html [Accessed September 2011

Dementia Services Development Centre (University of Sterling) (n.d.) Living Space [Online] Available from: http://dementia.stir.ac.uk/design_livingspace [Accessed September 2011]
Department of Health (2005) Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England [Online] London: The Stationery Office. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4106477 [Accessed September 2011]

Department of Health (2006) Best Practice Guidance on the role of Directors of Adult Social Services [Online] London: The Stationery Office. Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4134944.pdf [Accessed September 2011]

Department of Health (2006) Our Health, Our Care, Our Say: A new direction for community services [Online] London: The Stationery Office. Available from: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4127552 [Accessed September 2011]

Department of Health (2007) Putting people first: a shared vision and commitment to the transformation of adult social care [Online] London: The Stationery Office. Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf [Accessed September 2011]

Department of Health (2008) Transforming the Quality of Dementia Care: Consultation on a National Dementia Strategy [Online] London: The Stationery Office. Available from:

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085569 [Accessed September 2011]

Department of Health (2010) Equity and Excellence: Liberating the NHS [Online] London: DH. Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117794.pdf [Accessed September 2011]

Department of Health (2010) Liberating the NHS: Transparency in Outcomes – A Framework for the NHS [Online] London: DH. Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_117591.pdf [Accessed September 2011]

Department of Health (2010) Living Well with Dementia: A National Dementia Strategy. [Online] London:DH. Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_094051.pdf [Accessed September 2011]

Department of Health (2010) Nothing ventured, nothing gained: risk guidance for people with dementia. [Online] London: DH. Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_121493.pdf [Accessed September 2011]

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]

Department of Health (2011) Dementia Pilot TV Advertisement [video online] Available at: http://www.youtube.com/watch?v=TLpVqc0w_Ao [Accessed September 2011]

Department of Health (2011) Case for change – community-based services for people living with dementia: Evidence. [Online] London: DH. Available from:http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128570.pdf [Accessed September 2011]

Department of Health (2011) Common core principles for supporting people with dementia: a guide to training the social care and health workforce. [Online] London: Skills for Care, Skills for Health, DH. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127442 [Accessed September 2011]

Department of Health (n.d.) Shared Care Guidelines [Online] Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4898588 [Accessed September 2011]

Dilnot Commission (2011) Fairer Care Funding: The Report of the Commission on Funding of Care and Support. [Online] London: Dilnot Commission. Available from: https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf [Accessed September 2011]

Ferri, C.P. et al. (2005) Global prevalence of dementia: a delphi consensus study. Lancet. 366(9503):2112–2117

Foresight Mental Capital and Wellbeing Project (2008). Final Project report – Executive summary. London:The Government Office for Science. [Online] Available from: http://www.bis.gov.uk/assets/biscore/corporate/migratedD/ec_group/116-08-FO_b [Accessed September 2011]

Foresight (2011) The Rising Cost of Dementia. London:The Government Office for Science. [Online] Available from: http://www.sigmascan.org/Live/Issue/ViewIssue.aspx?IssueId=609&SearchMode=2 [Accessed September 2011]

Gilliard, J. *et al*. (2005) Dementia care in England and the social model of disability: lessons and issues. *Dementia*, *4*, 571–586.

Harvey, R.J. et al (2003) The prevalence and causes of dementia in people under the age of 65 years. Journal of Neurology, Neurosurgery and Psychiatry; 74: 1206–1209

Health and Social Care Bill 2011 [Online] London: The Stationery Office. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/HealthandSocialCareBill2011/index.htm [Accessed September 2011]

Health and Social Care Partnership South East (2011) Living well with dementia: A National Dementia Strategy: Compendium of Good Practice Across the South East [Online] HSCP. Available at: http://www.hscpartnership.org.uk/resources/dementia/SE_COMPENDIUM%20_OF%20_GOOD%20_PRACTICE.pdf [Accessed September 2011]

Healthcare at Home (2011) Understanding out of Hospital dementia care [Online] Staffordshire: Healthcare at Home. Available from: http://www.hah.co.uk/sites/default/files/upload/files/HAH_Report_web.pdf [Accessed September 2011]

House of Commons Committee of Public Accounts (2008) Improving Services and Support for People with Dementia: Sixth Report of Session 2007–08. [Online] London: House of Commons Available from: http://www.publications.parliament.uk/pa/cm200708/cmselect/cmpubacc/228/228.pdf [Accessed September 2011]

Kent County Council (2002) Culturally Competent Care [Online] Maidstone: KCC. Available from: https://shareweb.kent.gov.uk/Documents/adult-Social-Services/leaflets-and-brochures/culturally-competent-care.pdf [Accessed September 2011]

Kent County Council (2010) Bold Steps for Kent - The Medium Term Plan to 2014 [Online] Maidstone: KCC. Available from: https://shareweb.kent.gov.uk/Documents/priorities-policies-plans/Bold%20Steps%20for%20Kent/Bold%20Steps%20for%20Kent%20Dec%202010.pdf [Accessed September 2011]

Kent County Council (2010) Dementia 2010 Annual Public Health Report p14 [Online] Maidstone: KCC and NHS. Available from: http://www.kmpho.nhs.uk/easysiteweb/getresource.axd?assetid=160811&type=0&servicetype=1 [Accessed September 2011]

Kent County Council (2010) Developing an integrated health and social care commissioning strategy for older people in East Kent [Online] Maidstone: KCC and NHS. Available from: https://shareweb.kent.gov.uk/Documents/adult-Social-Services/care-services-in-Kent/integrated-health-social-care-commissioning-strategy.pdf [Accessed September 2011]

Kent County Council (2010) Kent Adult Carers Annual Report April 2009-March 2010 [Online] Maidstone:KCC. Available from: http://www.vam-online.org.uk/documents/kent-carers-annual-report-2009-2010.pdf [Accessed September 2011]

Kent County Council (2011) Charging for care provided at home (domiciliary care) Information for the public Valid from 11th April 2011 until April 2012 [Online] Maidstone: KCC. Available from:

https://shareweb.kent.gov.uk/Documents/adult-Social-Services/rates-and-charges/charging-for-care-provided-at-home.pdf [Accessed September 2011]

Kent County Council (2011) Race, Faith and Culture: A Support Toolkit [Online] Maidstone: KCC. Available from: https://shareweb.kent.gov.uk/Documents/adult-Social-Services/leaflets-and-brochures/faith-race-culture.pdf [Accessed September 2011]

Kent & Medway NHS and Social Care Partnership Trust (n.d.) Memory Assessment Service Model [Online] Available from: http://www.kmpt.nhs.uk/Downloads/Trust-Services/Memory-Assessment-Service-Model.pdf [Accessed September 2011]

The Kings Fund (2011) Briefing: The Health and Social Care Bill Report and Third Reading 6-7 September 2011 (p7) [Online] London: The King's fund. Available from: http://www.kingsfund.org.uk/current_projects/the_health_and_social_care_bill/ [Accessed September 2011]

Kitwood, T (1997) Dementia Reconsidered: the Person comes first. Open University Press

Knapp, M., et al (2007) Dementia: international comparisons. Summary Report for the National Audit Office. [Online] London: PSSRU. Available from: http://www.pssru.ac.uk/pdf/dp2418.pdf [Accessed September 2011]

Macdonald, A. J. D. et al (2002) Dementia and use of psychotropic medication in non-'Elderly Mentally Infirm' nursing homes in South East England. *Age and Aging*, 31, 58–64 [Online] Available from: http://ageing.oxfordjournals.org/content/31/1/58.full.pdf+html [Accessed September 2011]

Map of Medicine Ltd (2011) Dementia – Assessment [Online] Available from: http://healthguides.mapofmedicine.com/choices/pdf/dementia1.pdf [Accessed September 2011]

Mental Health Foundation (2011) Personalisation and dementia: A practitioner's guide to self-directed support for people living with dementia [Online] London: Mental Health Foundation. Available from: http://www.mentalhealth.org.uk/content/assets/PDF/publications/Dementia-Choices-Guide.pdf [Accessed September 2011]

Milne, A., Hamilton-West, K., and Hatzidimitriadou, E. (2005) GP Attitudes to Early Diagnosis of Dementia: Evidence of Improvement? Aging and Mental Health, 9(5) pp1-7

NAAPS UK Ltd (2010) The Shared Life of my choice [Online] Available from: http://www.naaps.co.uk/downloads/The_shared_life_of_my_choice_final.pdf [Accessed September 2011]

National Audit Office (2007) Improving Services and Support for People with Dementia [Online] London: The Stationery Office. Available from: http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx [Accessed September 2011]

National Audit Office (2011) Improving Dementia Services in England: An Interim Report [Online] London: The Stationery Office. Available from: http://www.nao.org.uk/publications/0910/improving_dementia_services.aspx [Accessed September 2011]

National Council for Palliative Care (2011) Difficult Conversations: Making it easier to talk to people with dementia about the end of life. p4 [Online] London: NCPC. Available from: https://www.committedgiving.uk.net/ncpc/publications/Product.aspx?id=358 [Accessed originally in Spring 2011 – there is now a charge for this publication]

National Skills Academy – Social Care (2011) Kent Alzheimers and Dementia Support Services wins top charity award [Online] Available from: http://nsasocialcare.co.uk/News/Latest-News/Kent-Alzheimers-and-Dementia-Support-Services-wins-top-charity-award/ [Accessed September 2011]

Newsam, M (n.d.) KCC Report on Short Term Bed Service [Online] Available from: http://democracy.kent.gov.uk/mgConvert2PDF.aspx?ID=18601 [Accessed September 2011]

NHS Choices (2011) Smoking linked to Alzheimer's risk [Online] Available at: http://www.nhs.uk/news/2010/10October/Pages/heavy-smoking-linked-to-alzheimers-risk.aspx [Accessed September 2011]

NHS Information Centre for Health and Social Care (2011) Establishment of Memory Services - Provisional Data (by email)

NHS Information Centre for Health and Social Care (2011) Establishment of Memory Services - Results of a survey of Primary Care Trusts, final figures, 2011 [Online] London: The Information Centre. Available from: http://www.ic.nhs.uk/webfiles/publications/005_Mental_Health/Memory%20Services%202011%20FINAL/Establishment_of_Memory_Services_results_of_a_survey_of_PCTs_2011.pdf [Accessed September 2011]

NHS Medway (2011) NHS Medway Operational Plan 2011-12 - Growing Healthier [Online] Available from: http://www.medwaypct.nhs.uk/explore-nhs-medway/about/board-meetings/the-nhs-medway-board/?categoryesctl3918978=5903&p=2 [Accessed September 2011]

NICE (2006) Dementia: A NICE-SCIE Guideline on supporting people with dementia and their carers in health and social care. National Clinical Practice Guideline Number 42. [Online] London: The British Psychological Society
& The Royal College of Psychiatrists. Available from: http://www.nice.org.uk/nicemedia/pdf/CG42Dementiafinal.pdf [Accessed September 2011]

NICE (2009) Quality and Outcomes Framework (QOF) Indicator Development Programme Briefing paper: Learning Disability [Online] London: NICE. Available from: http://www.nice.org.uk/media/F40/35/QOFAdvisoryCommitteeBriefingPaperLearningDisability.pdf [Accessed September 2011]

Office for National Statistics (2010) Statistical Bulletin: Internet Access 2010 Households and Individuals [Online] Available from: http://www.e-learningfoundation.com/Websites/elearningfoundation/Images/PDF%20Documents/ONS%20Internet%20Access%202010.pdf [Accessed September 2011]

REPoD (2010) A Guide to Setting up a Memory Café [Online] Available from: http://www.repod.org.uk/downloads/REPoD%20guide%20to%20setting%20up%20a%20Memory%20Cafe.pdf [Accessed September 2011]

Royal Commission on Long Term Care (1999). With respect to old age : long term care – rights and responsibilities. [Online] London: The Stationery Office. Available from: http://collections.europarchive.org/tna/20081023125241/http://www.archive.official-documents.co.uk/document/cm41/4192/4192.htm [Accessed September 2011]

Rusanen, M et al (2011) Arch Intern Med. 2011;171(4):333-339. doi:10.1001/archinternmed.2010.393 Abstract [Online] Available from: http://archinte.ama-assn.org/cgi/content/short/archinternmed.2010.393 [Accessed September 2011]

Seabrook, V & Milne, A (2004) Culture and Care in Dementia: A Study of the Asian Community in North West Kent. Unpublished.

Surrey County Council (2009) Young Onset Dementia Services in Surrey Commissioning Strategy 2009-2014 [Online] Available from: http://www.fadingmemories.surreyhealth.nhs.uk/downloads/Young_Onset_document.pdf [Accessed September 2011]

Thomas-Sam, M (2010) KCC Report to SMT Health: Dementia Services Healthcheck (Unpublished)

U.S National Institute on Aging (2011) Alzheimer's Disease Information for Children and Teens: A Resource List [Online] Available from: http://www.nia.nih.gov/Alzheimers/Resources/Lists/children.htm [Accessed September 2011]

Vyas, H (n.d.) Presentation: Salford Care Homes Practice. [Online] London:Royal College of Nursing. Available from: http://www.rcn.org.uk/__data/assets/pdf_file/0011/360875/2.1.1_Helen_Vyas.pdf [Accessed September 2011]

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