

HEALTH AND ADULT SOCIAL CARE OVERVIEW AND SCRUTINY COMMITTEE

27 JANUARY 2015

DEMENTIA STRATEGY

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Summary

This report presents an update of the draft Dementia Strategy originally presented to Health and Social Care Overview and Scrutiny Committee on 30 September 2014. The report outlines the consultation that has taken place and further work that will be undertaken to ensure that the actions outlined in the strategy are progressed.

The report provides an opportunity for Overview and Scrutiny Committee Members to be consulted on the final draft before it goes to Cabinet on 10 February 2015.

1. Budget and Policy Framework

- 1.1 The Joint Health and Wellbeing Strategy for Medway 2012 – 2017 sets out as a vision that “older people feel valued and supported in their local communities”. The four underlying principles underpin all health and wellbeing work in Medway. These have been incorporated into the draft Medway Dementia Strategy – Living well with Dementia in Medway (attached at Appendix 1 to this report).
- 1.2 One of the five strategic themes of the Joint Health and Wellbeing Strategy is to enable our older population to live independently and well. The Council Plan also contains the priority that ‘Adults maintain their independence and live healthy lives’. Approval of the Dementia Strategy is a matter for Cabinet.
- 1.3 The Medway Health and Wellbeing Board has a Dementia Delivery Plan and this Strategy focuses on the following key elements to improvement:
 - Make Medway a Dementia Friendly Community
 - Understand the current health and social care needs of people in Medway living with dementia
 - Develop a Medway Dementia Strategy
- 1.4 The Medway Dementia Strategy has been developed with the specific aim of achieving the following outcomes:

- 1.4.1 People with dementia are able to 'live well' and feel empowered to have high aspirations, confidence and know they can contribute;
- 1.4.2 Commissioning processes are evidence based and reflect current need;
- 1.4.3 A clear partnership commissioning strategy upon which intelligent and responsive services are created, maintained and developed to ensure an enhanced quality of life for people living with dementia and their carers;
- 1.4.4 A dementia pathway that will provide timely interventions that focus on early diagnosis reducing admissions to hospital and mental health units and averts crises;
- 1.4.5 Improved quality of care for patients in acute hospitals and supported early discharge; and
- 1.4.6 High quality care for adults with dementia at the end of their lives.

2. Background

- 2.1 Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing.
- 2.2 There are a number of types of dementia, which are caused by different diseases of the brain. These different types of dementia are associated with different risk factors. The most common type is Alzheimer's disease, affecting about 62% of those with dementia.
- 2.3 In the Medway Local Authority area in 2012, it was estimated that 2,587 people were living with dementia, with 2,523 over 65 years old. The severity of dementia is normally classified as mild, moderate or severe. At any one time about 55% of the population who have dementia will have mild dementia, 32% moderate dementia and 13% severe dementia.
- 2.4 63.5% of people with late onset Dementia (aged 65 years and over) live in private households (the community) and 36.5% live in care homes. Applying these percentages to current Medway estimates, suggests that about 1,590 people with dementia are living in the community and 932 in care homes.
- 2.5 Between 2012 and 2037, the number of older people living in Medway with Dementia is expected to increase from approximately 2,500 to 5,600. This is driven by projected changes in the age structure of the population.

3. Analysis and advice

- 3.1. Key to the Dementia Strategy is the need to develop a greater community awareness and understanding of dementia illnesses and the effect dementia has on people's lives as well as the importance of focusing on 'living well with dementia' and developing earliest possible interventions. The development of a local Dementia Action Alliance will help greatly in developing wider and deeper community awareness and understanding of dementia.

- 3.2. The challenge of dementia is not solely a health and social care one. It is a challenge that the whole community of Medway faces and action in response to this challenge needs to be taken by the community as a whole. To support the notion of developing Medway as a dementia friendly community Medway Council and Medway CCG have funded the Alzheimer's Society to set up and develop a Dementia Action Alliance. This is a pilot project funded for one year, which will be reviewed at the end of the year to look at long term sustainability of the Alliance.
- 3.3. The DAA becomes the vehicle by which the community as a whole can successfully reach the destination of becoming a dementia friendly community. The DAA is owned and driven by its component members and whilst the Strategy and commissioning options will support and facilitate the creation of the DAA, sustaining it becomes the responsibility of the DAA itself.
- 3.4. A dementia-friendly community is one in which people with dementia are empowered to have aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.
- 3.5. Nationally a great emphasis is being placed on the early diagnosis of dementia to ensure that people can be provided with treatment and interventions at the earliest possible opportunity. Greater community awareness of dementia and the benefit of early diagnosis will help to improve the diagnosis rate.
- 3.6. The role of the GP in the success of a Dementia Strategy is critical. When a person with a developing dementia illness becomes concerned they will most likely approach their GP in the first instance. The GP's understanding of dementia, its effect on those living with it and the benefit of early diagnosis, together, are fundamental to ensuring that the journey a person makes starts off in the best possible way. The trust and confidence established between patient and GP is likely to dictate the quality of life a person experiences as their condition develops. GPs play a vital role not only in ensuring early diagnosis but in ensuring that well-planned and co-ordinated community services are in place to help people after diagnosis – this is part of the shared care model of patient focused care and support that needs to be enhanced in Medway.
- 3.7. Better care for people living with dementia is about supporting people and their carers to live 'well' which means maintaining a person's familiar and cherished lifestyle for as long as possible. Where interventions are necessary these should be delivered sensitively and at the earliest point, with crises being managed effectively to avoid inappropriate disruptions to wellbeing arising from avoidable admissions into secondary care and/or care homes.
- 3.8. In 2012, an estimated 21 million people nationally know a close friend or family member with dementia – that is 42 percent of the population. There is an estimated 550,000 carers of people with dementia in England with an expectation that one in three people are likely to care for a person with dementia at some point in their lifetime.

- 3.9. The key to ensuring that activity is knitted together is the coherent implementation of the strategy. Partnership and working together are essential.

4. Actions outlined in the Strategy

- 4.1 Medway residents and particularly those people who are living with dementia will be continually involved in the implementation of the Dementia Strategy. This will be a key aim of a local Dementia Action Alliance and will occur at regular intervals in recognition that the Strategy is a 'living breathing' document that needs to reflect the changing needs of the Community.
- 4.2 Community awareness of dementia will be developed by continuing to support national Dementia Awareness campaigns such as the ongoing Public Health England Dementia Friends initiative, which is being promoted by the Alzheimer's Society and endorsed by the Prime Minister. The Dementia Strategy recognises the importance and benefit of developing a greater understanding of dementia illnesses and the challenges that people living with dementia face on a daily basis. It is proposed that a local Dementia Action Alliance is established to support greater understanding by bringing the community of Medway together to work collectively on common aims.
- 4.3 A local Dementia Action Alliance will be the vehicle to bring the community of Medway together. Organisations will be asked to create individual action plans as well as agree a common set of aims. The alliance will create an opportunity for relationships between people and organisations to grow and develop into action that will change and improve the quality of life for people living with dementia. Medway Council and NHS Medway CCG will commission a voluntary sector organisation to have a co-ordination function.
- 4.4 The Strategy supports the recommendation of the All-Part Parliamentary Group's report – Building on the National Dementia Strategy: Change, progress and priorities:

Every CCG and local authority should appoint a Dementia Lead with specific responsibility to ensure high-quality dementia services. This function is currently sitting within Partnership Commissioning. When planning and commissioning services, CCGs and local authorities, should:

- use evidence
- assess local dementia needs
- engage with people affected by dementia and use their personal stories
- share data effectively and safely
- consider dementia services in applications for the Better Care Fund.

- 4.5 Ensuring that initiatives are based on the best possible clinical research and evidence is critical. Through our Partnership Commissioning work we will continue to ensure that links are maintained locally, regionally and nationally with expert bodies.
- 4.6 Progress with the development of an audit process using Audit + (a clinical data audit and data analysis tool available to most GP Practices in Medway) will continue together with the development of guidance and support to GPs

to ensure that data collection for people with dementia including the use of anti-psychotic medication, is as accurate and up to date as possible.

- 4.7 Medway Council and CCG will prioritise post-diagnostic support for people affected by dementia. This includes personalised advice, information and support, and ensuring that people with dementia know what to expect following a diagnosis. The Better Care Fund will be as an opportunity to integrate services in order to improve outcomes for people with dementia.
- 4.8 The critical role of the GP should be recognised and work continued to support development of greater understanding
- 4.9 The aims of the Carers Call to Action will be supported and endorsed. A local Dementia Action Alliance will promote the actions required to ensure these aims are achieved.
- 4.10 The recommendations of the dementia-friendly technology charter are supported:
- The right to a care assessment should always include a consideration for dementia-friendly technology
 - A single, simple to use and regularly updated online resource detailing dementia-friendly technology should be developed
 - Accessible and easy to find information that lists where dementia-friendly technology is available in the local area – including a link to the Charter
- 4.11 A local Dementia Action Alliance can support and develop the way in which agencies that provide services work together to form a coherent, safe and clear pathways for people whose needs develop as they live with the progressive effects of dementia. The work being undertaken to develop the Map of Medicine into a tool that provides GPs with a way of directing health and social care support will assist the development of clear pathways. Close work is required to ensure the changes to health and social care structures assist the development of closer work between GPs, healthcare professionals and social care professionals.

5. Consultation

- 5.1 This update of the Dementia Strategy has taken evidence from a broad range of stakeholders and organisations. The Strategy was circulated for consultation to all Medway Councillors, Parish Councillors, internal departments within the Council, social work teams and health and social care commissioners. The voluntary sector also received the Strategy so that they could seek comments from their constituent members and those who use their services.
- 5.2 Consultation has taken place with a wide range of stakeholders, particularly direct consultation with people living with dementia and their carers. The draft Strategy was presented at GP monthly and brought to Health and Adult Social Care Overview and Scrutiny on 30 September 2014. The draft Strategy was then circulated for further consultation until 30 November 2014.

- 5.3 Medway Council must comply with its obligations to equalities under the Equality Act 2010, to eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by this Act. It must advance equality of opportunity and foster good relations between people. This involves removing or minimising disadvantages suffered by people, including taking steps to meet the needs of people from people who have a “protected characteristic” in the terms of this Act. It must encourage people from protected groups to participate in public life and other activities where their participation is disproportionately low. In order to comply with these equality duties, the Council is required to engage with service users and representative groups, and to use the information and views gathered to assess the equality impact of any proposals made by the Council in relation to service provision.
- 5.4 Officers will complete a Diversity Impact Assessment (DIA) following the work of the Implementation Plan being developed and completed and commissioning recommendations being made.

6. Further Work

- 6.1 An implementation plan is currently being developed to ensure that the actions outlined in the Dementia Strategy are supported. The work streams outlined in the Implementation Plan will also support the development of commissioning recommendations and associated costs for dementia services. The implementation plan, along with commissioning recommendations, will be presented to Health and Adult Social Care Overview and Scrutiny Committee for consultation on 31 March 2015 before going to Cabinet for decision on 14 April 2015.

7. Risk management

Risk	Description	Action to avoid or mitigate risk	Risk rating
DAA is not self sustaining at end of funding period	DAA is funded for one year. At the end of the funding period DAA must be able to continue to support Medway to be dementia friendly	Robust KPI's are being developed and will be monitored monthly during funding period	Low
Commissioning of dementia services may be delayed	Timescale for agreed commissioning intentions may not be met.	Implementation plan is being developed. Steering group is being set up to oversee plan. Risk register has been drafted and will be monitored	Low

8. Financial implications

- 8.1 The cost of Dementia Services and Support is met through existing revenue budgets, although some services may form part of the Better Care Fund from 2015/16.

9. Legal implications

- 9.1 There are no specific legal implications arising from this report.

10. Recommendations

- 10.1 The Committee is asked to note this update on the changes to the Dementia Strategy and the actions outlined in the revised draft Strategy made to improve the quality of life for people living with dementia in Medway.
- 10.2 The Committee is recommended to refer the Dementia Strategy, as attached at Appendix 1 to this report, to Cabinet on 10 February 2015 for approval.

Background Papers:

Alzheimers Society,
http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=341,
accessed September 2014

World Health Organisation,
<http://www.who.int/mediacentre/factsheet/fs362/en/>, accessed September 2014

Emiliano DA, Banerjee PS, Dhanasiri S, et al. Dementia UK: The Full Report 2007; Alzheimer's Society.
<http://alzheimers.org.uk/site/scripts/download.php?fileID=2>

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Living Well with Dementia in Medway

Medway Dementia Strategy

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1. Dedication

This strategy is dedicated to the people of Medway who are living with dementia.

The challenge of dementia is something that faces our whole community but it is those people living with the illness or caring for someone with the illness who face the reality of that challenge on a daily basis.

It is the dedication, determination and love shown by those people living with dementia who have inspired this strategy and it is for those people now and those who will face the challenge in the future that the recommendations for action have been written.

The Case Study below demonstrates why people in Medway who are living with dementia must be at the centre of what we do.

Public Health Case Study

Mr B, a retired professional, has lived in Medway along with his wife of many years. Living in retirement Mr and Mrs B enjoyed time with their children and met up with old friends from time to time. On one occasion when they met up with friends they hadn't seen for a year that one of them took Mr B to one side and asked him if he had noticed anything unusual about Mrs B's memory, which he hadn't. Mr B had thought that his wife's forgetfulness was nothing extraordinary or worrying. The friend had developed an awareness around dementia through having seen a close family member develop the condition. It was this awareness that made the friend tell Mr B that his wife was showing the signs of what was very likely to be a dementia disease.

Mr and Mrs B spoke about this and they arranged to speak with their local GP who made a referral to the local memory assessment service for a series of tests. A brain scan at the local hospital, together with the results of the test and Mr B's description of changes in his wife over time led to a diagnosis of vascular dementia with Alzheimer's disease.

Mr and Mrs B were both offered counselling and support in the form of a ten-week programme where each separately learnt about the likely progression of the disease and how to manage this in their lives with the aim of living as well as possible with dementia. Mrs B was a member of her local Women's Institute and the group were committed to continuing her involvement 'come what may'. It was this support and commitment of her close circle of friends that allowed Mrs B to maintain her independence for as long as possible. At that time both Mr and Mrs B were able to look forward to the regular visits of the local Admiral Nurse. Having someone come to the home and talk to them both about how the disease was affecting their lives was very valuable, and increasingly so to Mr B who was now his wife's main carer, a position that occupied his life totally.

As the disease began to have an increasing effect on Mrs B's abilities, a place at a local day centre was arranged with the support of Adult Social Care staff, but a further decline in health resulted in Mrs B experiencing hallucinations, that made her too worried to leave her house. The disease progressed to the point where more help was required and Mr B was offered a further support to

understand how profound the effect would be on his wife's abilities. Further assistance was arranged by Adult Social Care and paid carers visited once a day to help in the morning and occasional respite was arranged.

Inevitably the disease took control of their lives and Mrs B became increasingly frail and confused. Successive falls led to hospital treatment and a general decline in Mrs B's physical health. At that time services were not always understanding of the special needs of people living with dementia and Mr B set about challenging services to recognise the person behind the dementia and convincing people to become part of a campaign to increase awareness and improve services.

As Mrs B's health deteriorated Mr B was offered a final course of counselling and support that prepared him for his wife's end of life. Increasing frailty, the risk of further falls and increased confusion and disassociation from the world took Mr B to a time when he sat down and spoke with his children and made the agonising decision that his wife's needs could now only be met with the 24hr support that a nursing home could provide.

The nursing home supported Mrs B to continue to be involved in daily life and encouraged her to fold laundry and supported her desire to help keep the house looking tidy. However as the disease continued to affect Mrs B's abilities further falls resulted in a dramatic deterioration in physical health and concerns about her health led to an admission to A&E where Mr B faced the loss of his wife as her body failed and he saw her through her final moments.

Mr and Mrs B's story is one experienced by an increasing number of people and Mr B continues to live with the effects of dementia. Through the journey that they both faced there were times when the services, care and support received were outstanding, but at other times were moments of great anxiety and anger at the lack of understanding that was shown toward a person with dementia. Not one for sitting quietly, Mr B challenged services then and continues to do so now. The challenge of dementia is one faced by an increasing number of people and one which needs to be recognised by whole communities. It is through the actions of individuals and the ability of communities to listen and respond that the quality of life of those living with dementia will be improved.

2. Foreword

Medway Council and NHS Clinical Commissioning Group, through our Partnership Commissioning work, are very pleased to present this Dementia Strategy for consultation.

According to Alzheimer's Society^[1] there are approximately 670,000 people in England who are living with dementia and this figure is expected to double in the next 30 years. In 2012 there was an estimated 2,587 people with dementia and an expectation that this will rise to 5,600 by 2037.

The World Health Organisation^[2] estimated in 2010 that there were 36 million people living with dementia worldwide with an expectation that this figure would double every twenty years. The cost of meeting the challenge of dementia in 2010 was calculated at 1% of global GDP.

It is very clear that the challenge of dementia is an enormous one and the importance of developing a clear strategy cannot be underestimated. There are many examples of excellent care and support in Medway but there is often an absence of agencies working together to ensure that people living with dementia can continue to live well by being offered a clear pathway from earliest diagnosis through to end of life. The way that we will rise to the challenge and achieve better outcomes for people is to work together – here the relationships between people and organisations become key.

We have worked closely together in partnership to ensure that both health and social care perspectives have been drawn upon in the development of this document. However as you will see the challenge of dementia is not just a health and social care matter; it is a concern for the whole of the community of Medway. We have during the development of this strategy met with representatives of many organisations as well as people living with dementia. We believe that this strategy provides the foundation for the community Medway to develop both a better understanding of dementia and ways that the challenges of this condition can be met.

To be signed: Lead Member for Adult Services
and Health

Signed off by CCG representative

3 Purpose of the Document

The purpose of the Dementia Strategy is to set out a clear direction of travel for change for dementia care and support services. The strategy will form a basis upon which commissioning decisions can be made. The Strategy provides a set of guiding principles that pull together national initiatives, local needs and aspirations, and best practice in supporting people living with dementia.

It is expected that, by implementing the Dementia Strategy and adopting the recommendations, the future for people living with the challenge of dementia in Medway will provide:

- **A place to live that is a dementia friendly community**
- **A sense of worth and inclusion in a community that understands**
- **A caring and supportive environment within which needs are recognised**
- **A commitment from professionals to work together to meet people's needs**
- **A community that works together as an alliance to create resilience that rises to the challenge of dementia**

4. Introduction

4.1 What is Dementia?

The World Health Organisation (WHO) provides the following definition:

Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing.

WHO, 2014

Dementia is a global term used to describe a range of neurological disorders characterised by a decline in intellectual and other mental functions. It can affect people of any age, but is most common in older people and age is the greatest risk factor for dementia.

The table below shows estimated prevalence rates from the most recent consensus exercise^[3] broken down by age group. Most dementia is late onset (affecting people aged 65 and over) with about 1 in 40 cases being early onset (up to the age of 64 years).

	Female rate per 100,000 population	Male rate per 100,000 population
30-34	9.5	8.9
35-39	9.3	6.3
40-44	19.6	8.1
45-49	27.3	31.8
50-54	55.1	62.7
55-59	97.1	179.5
60-64	118.0	198.9

	Female percent	Male percent
65-69	1.0	
70-74	2.4	
75-79	6.5	
80-84	13.3	
85-89	22.2	
90-94	29.6	
95+	34.4	

Need to put in new chart as male figures are missing

Table 1: Prevalence of early onset dementia in the UK by age and gender under 65^[3]

Table 2: Prevalence of late onset dementia in the UK by age and gender 65 and over^[3]

Tables 1 and 2 highlight the importance of age as the key risk factor for dementia. 1–1.5% of 65–69 year olds are likely to have dementia compared with 30–35% of adults over 95. The prevalence of dementia increases significantly with age. A higher proportion of females experience dementia than males.

Early onset dementia can be linked to learning disabilities and there is also a suggestion of increasing levels of alcohol related dementia. Not only can people with learning disabilities have an increased risk of developing dementia but the early stages of the condition can be missed or misinterpreted. As people with learning disabilities are living longer there is an increasing need for awareness and early detection of the condition. A study of people with Down's Syndrome found the following prevalence of Alzheimer's disease:^[4]

- 30–39 years: 1 in 50
- 40–49 years: 1 in 10
- 50–59 years: 1 in 3
- 60–69 years: more than half

Studies have also shown that in later life almost all people with Down's Syndrome develop the changes in the brain associated with Alzheimer's disease, although not all develop the symptoms of Alzheimer's.

Studies suggest the numbers of people with learning disabilities other than Down's Syndrome who have dementia are approximately:^[4]

- 50–65 years: 1 in 10
- 65–75 years: 1 in 7
- 75–85 years: 1 in 4
- 85+ years: nearly three-quarters

These numbers indicate a risk about three to four times higher than in the general population.

The rate of cognitive problems has been found to be higher in people of lower socio-economic class and lower educational achievement.^[5]

Early onset dementia can also be linked to increasing levels of alcohol related dementia. This is important particularly with respect to Korsakoff's dementia which is reported to affect 12.5% of dependent drinkers.

Types of dementia

There are a number of types of dementia which are caused by different diseases of the brain. These different types of dementia are associated with different risk factors.

The most common type is Alzheimer's disease, affecting about 62% of those with dementia. Vascular dementia (17%), including multi-infarct dementia and Lewy Body dementia, are the next most common forms as well as mixed presentations. About 10% of people with dementia have both Alzheimer's disease and vascular dementia.

	Proportion of people with dementia
Alzheimer's disease	62
Vascular dementia	17
Mixed (AD and VD)	10
Dementia with Lewy bodies	4
Frontotemporal dementia	2
Parkinson's dementia	2
Other	3

Table 3: Types of dementia^[1]

(i) Alzheimer's

A physical disease affecting the brain leading to the death of brain cells. It is a progressive disease that becomes more severe over time. It is characterised by confusion and memory loss, mood swings, social withdrawal and poor social functioning.

The primary risk factor is age. There is some evidence of genetic factors and also smoking and hypotension have been linked to increased risk of getting Alzheimer's.

People with Down's Syndrome have increased risk of getting Alzheimer's due to chromosomal abnormalities.

(ii) Vascular Dementia

Certain factors can increase a person's risk of developing vascular dementia. These include:

- a medical history of stroke, high blood pressure, high cholesterol, diabetes (particularly type II), heart problems, or sleep apnoea (where breathing stops during sleep)
- a lack of physical activity, drinking more than recommended levels of alcohol, smoking, eating a fatty diet, or leaving conditions such as high blood pressure or diabetes untreated
- a family history of stroke or vascular dementia
- gender - men are slightly more likely to develop vascular dementia
- an Indian, Bangladeshi, Pakistani, Sri Lankan or African Caribbean ethnic background

(iii) Mixed dementia — Alzheimer's and Vascular

It is estimated that this form of dementia consists of 10% of the total number of people diagnosed with a dementia.

(iv) Dementia with Lewy Bodies (DLB) and Parkinson's Disease Dementia (PDD)

If symptoms of dementia are noted within a year of the person being diagnosed with Parkinson's, a diagnosis of DLB will be made. This is caused by tiny spherical protein deposits that develop inside nerve cells in the brain. These interrupt the brains normal functioning affecting the person's memory, concentration and language skills. If the symptoms appear over a year after the Parkinson's diagnosis, a diagnosis of PDD will be given.

(v) Korsakoff's / Alcohol-related dementia

Those affected tend to be men between the ages of 45 and 65 with a long history of alcohol abuse. Although numbers affected by Korsakoff's are small (component of 'other' forms of dementia which make up 3% total cases), it is reported to affect 12.5% of dependent drinkers and has implications for health and social care services as it affects a younger age group where dementia support is traditionally targeted at older people.

(vi) Other dementias

Included in this are Fronto-Temporal Dementia (2% of total) along with less common types such as CJD.

In the Medway Local Authority area in 2012, there were estimated to be 2,587 people living with dementia with 2,523 being over 65 years old. The number estimated for the registered population for Medway CCG is 2,783. Data from the Quality and Outcomes Framework primary care dementia registers in 2012/13 have only identified 1,332 patients in Medway as having dementia. The estimated prevalence of dementia for Medway CCG population is 47.87%, which is higher than the Kent and Medway average of 42.94% and the South of England average of 45.65%.

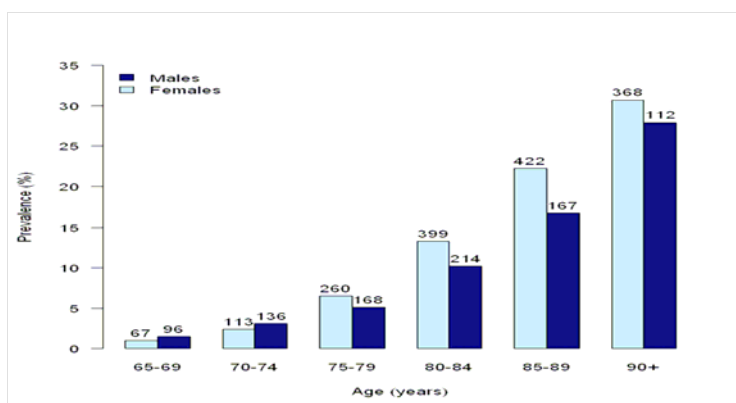


Figure 1: Estimated prevalence of Dementia in people aged 65 years and over^[6] Notes: Age-sex prevalence estimates have been taken from Dementia UK 2007 report produced for the Alzheimer's society by King's College London and the London School of Economics.^[1] The prevalence rates have been applied to ONS population projections of the 65 and over population to give estimated numbers of people predicted to have dementia in 2012. These numbers are shown above the bars.

Severity of need

The severity of dementia is normally classified as mild, moderate or severe. At any one time about 55% of the population who have dementia will have mild dementia, 32% moderate dementia and 13% severe dementia.^[3] Table 4 shows this in more detail broken down by age group. Applying the

estimates in the first column to the Medway population numbers, the second column shows the estimated total number of people in 2012 with mild, moderate and severe dementia.

	Mild		Moderate		Severe	
	Number	Percentage	Number	Percentage	Number	Percentage
65-69	101	62	52	32	10	6
70-74	157	63	75	30	17	7
75-79	244	57	133	31	51	12
80-84	349	57	196	32	67	11
85-89	318	54	194	33	77	13
90+	226	47	158	33	91	19

Table 4: Dementia severity in Medway by 65 and over age-groups (2012 numbers) ^{[6] [3]}

Level of need for care

Many of those with severe dementia, especially those over 85, have a combination of mental and physical problems.^[7] On average, people with dementia live for seven or eight years after the problem has been first diagnosed, although there are wide individual variations.^[7]

The Dementia UK 2007 report ^[3] estimates that 63.5% of people with late onset Dementia (aged 65 years and over) live in private households (the community) and 36.5% live in care homes. Applying these percentages to current Medway estimates, suggests that about 1,590 people with dementia are living in the community and 932 in care homes.

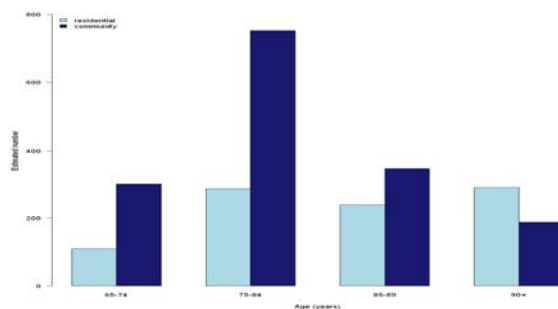


Figure 2: Estimated number of people with dementia in Medway by residence type ^[3]

Another way of understanding the level of need for care is to use the concept of "interval of care"^[8] developed for use with older people. Using these classifications the table below shows the number of people in Medway aged 65 and over currently in these groups

Care interval description	Requirement	Proportion of people with dementia	Number of people in Medway
critical (critical interval)	constant care or supervision needed	34%	858
substantial (short interval)	care needed at regular intervals during the day for dressing, meals etc	48%	1,211
moderate (long interval)	care needed once a week	11%	278

low (independent)	care considered	6%	151
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Table 5: Care intervals^[9]

4.2 Why Do We Need a Dementia Strategy?

Supporting people who are living with dementia, both the person with the illness and carers, helps people to live well, and avoids the need for health and social care interventions which are likely to be costly and disruptive.

The Strategy is one part of improving the care and support for people living with dementia. The Medway Health and Wellbeing Board have a Dementia Delivery Plan that identifies the following key elements to improvement:

- ✓ Make Medway a Dementia Friendly Community
- ✓ Understand the current health and social care needs of people in Medway living with dementia
- ✓ Develop a Medway Dementia Strategy
- ✓ Develop an Implementation Plan

The Medway Dementia Strategy has been developed with the specific aim of achieving the following outcomes:

1. People with dementia and their carers' are able to 'live well' and feel empowered to have high aspirations, confidence and know they can contribute
2. Ensure commissioning processes are evidence based and reflect current need
3. A clear partnership commissioning strategy upon which intelligent and responsive services are created, maintained and developed to ensure an enhanced quality of life for people living with dementia and their carers
4. A dementia pathway that will provide timely interventions that focus on early diagnosis reducing admissions to hospital and mental health units and averts crises
5. Improved quality of care for patients in acute hospitals and supported early discharge
6. High quality care for adults with dementia at the end of their lives

The Dementia Strategy will build on the expressed experiences and aspirations of people living with dementia which will include carers as well as supporting practitioners, advocates and community group representatives. Stakeholder events, participation in existing user forums and communication strategies have taken place to ensure engagement is meaningful. An integrated approach means that engagement is also being developed across work themes (e.g. in relation to the Better Care Fund's community services re-design). A link has been established with Medway Healthwatch to ensure their perspective as a 'critical friend' is maintained.

4.3 What people living with dementia have told us

In March 2012 a report was produced for Medway Link by Link Market Research http://www.themedwaylink.co.uk/assets/files/Publications/Project_reports/Accessing_Dementia_Services_in_Medway_Version_2.pdf

The executive summary of this report identifying the four key themes (see below). The report attempted to ascertain the views of carers, providers and people with dementia but struggled to access views from people with dementia. 14 Medway carers were interviewed as part of this work as well as and 10 providers of care. The findings from the report remain relevant and have in essence been echoed by recent engagement with organisations, professionals, carers and people with dementia.

There are some strong themes emerging from this piece of research which were echoed by both carers and providers:

1. A lack of continuity throughout the dementia journey from diagnosis to end of life
2. Services fragmented - too many different services not working together
3. Greater professional understanding and awareness with more personalised care / attention to those with dementia
4. More public awareness about dementia and reducing the stigma associated with the disease.

1. A lack of continuity throughout the dementia journey from diagnosis to end of life

The general consensus amongst carers and provider, is that the services on offer are not consistent and do not adapt as the condition worsens. Post diagnosis people generally felt that the services were adequate and it was possible to cope, however this was more to do with the condition being relatively early in its stages and therefore much easier psychologically and physically to access the services on offer. Furthermore, with the sufferer being more aware, this meant the effectiveness of the service was higher and there was less demand on the carer. As the condition worsened, the general feeling was that it became more difficult to access the types of services which would have made a difference. In the later stages people felt there was limited emergency help and advice twenty four/ seven and that practical help is sometimes needed at all times, to quote "dementia is not 9.00am to 5.00pm".

An extension to this theme addressed early onset dementia. Those with this condition often fell into "no man's land" because they were not considered elderly enough to access some of the dementia services on offer to them, or the services on offer were not appropriate due to the age of the person:

"There appears to be a need to address the gap in service provision from early stages to later stages when the condition is more demanding as well as age considerations in terms of younger people getting dementia and offering services more appropriate for their age".

2. *Fragmented - too many different services not working together*

Both carers and providers felt that there were lots of services out there but that none of them were joined up. This results in confusion because people are either passed from pillar to post or they don't know where to start asking for help. The variety of services available is not the issue; it is the lack of communication between them which makes the process patchy. It does not necessarily matter where the person enters the system, as long as they are sign posted to the most appropriate service. Alternatively, people felt there should be a central office / contact that could then refer them onto the most appropriate service or individual.

Ambivalence can be seen in some of the scoring of the provision of dementia services locally, with scores hovering around the midpoint and tipping slightly towards dissatisfaction. This seems to be more associated with the process one has to go through to get into the system, rather than the quality of the service itself once you are there:

"More co-ordinated provision of services is needed - a central office or greater communication between services to guide carers / people with dementia through the system to the most appropriate service".

3. *Greater professional understanding and awareness with more personalised care / attention to those with dementia*

Overall, people felt more training was needed amongst professional staff across the board, this included hospital staff, doctors and care staff. As an example, a person may require medical attention that is separate to their dementia illness and often carers felt staff did not recognise or understand that a dementia patient will act differently to patients who do not have dementia on the ward. In addition to this, people felt dementia care cannot be generalised; it needs to be specific to the person who has dementia:

"More recognition of dementia within the professional environment and greater understanding of behavioural changes. Provision of services which offer more personalised activities tailored to individuals rather than generalised day centres to cater for all. Clearly this needs to be balanced with the feasibility of bespoke servicing but a greater understanding of the disease could highlight the benefits of providing more stimulating social activities and improving the quality of life for both carer and patient".

4. *More public awareness about dementia and reducing the stigma associated with the illness*

There still appears to be a stigma associated with dementia which influences the effectiveness of the services on offer because people are not yet willing to admit they need help or their loved one needs help. Coupled with this, there is limited knowledge of the condition which makes it a daunting prospect to tackle and often problems are kept hidden as a result.

There is also a sense of determination to just "get on and cope with it"; that it is "part and parcel" of one's commitment to their loved one to care for them. Whilst this is commendable, it seems people cope until they reach crisis point and the situation starts to break down. The offer of appropriate and earlier support could go some way to supporting carers earlier, thus preventing them from reaching this stage. This will require action to change people's perception of dementia and a recognition that these services are there to enhance the quality of life for both them and their loved one.

Local stakeholder events that have been held recently have echoed the findings above and have indicated that some support services are working well but there is a need for more support to carers, better information, earlier diagnosis but with additional support, clear pathways to services and better integration and coverage of what is available to ensure equality of

opportunity across Medway. The absence of services for people with a learning disability who also develop a dementia illness was highlighted as a significant issue.

Action 1

Medway residents and particularly those people who are living with dementia will be consulted on the Dementia Strategy. This will be a key aim of a local Dementia Action Alliance and will occur at regular intervals in recognition that the Strategy is a 'living breathing' document that needs to reflect the changing needs of the Community.

Healthwatch Medway will be asked to facilitate this consultation using their relationship with the Council and NHS as a 'critical friend'.

5. National Context

Key facts

- Dementia is a syndrome in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities
- Although dementia mainly affects older people, it is not a normal part of ageing
- Worldwide, 35.6 million people have dementia and there are 7.7 million new cases every year
- Alzheimer's disease is the most common cause of dementia and may contribute to 60–70% of cases
- Dementia is one of the major causes of disability and dependency among older people worldwide
- Dementia has physical, psychological, social and economic impact on caregivers, families and society

WHO, 2014

Nationally a growing imperative has been established that recognises the increasing challenge that dementia presents. In 2009, the first national Dementia Strategy was published and more recently the All-Party Parliamentary Group on Dementia has recommended that a new long term strategy is developed. The Prime Minister has since 2012 has highlighted the issue of dementia and set out his 'challenge on dementia' that aimed to deliver sustained improvements in health and social care, create dementia friendly communities and boost dementia research.

In 2009 the Department for Health published *Living Well with Dementia: a national dementia strategy*¹³. The intention of this strategy was provide a strategic framework within which local services could:

- deliver quality improvements to dementia services and address health inequalities relating to dementia
- provide advice and guidance and support for health and social care commissioners and providers in the planning, development and monitoring of services
- provide a guide to the content of high-quality services for dementia

In 2012 the Prime Minister launched his Dementia Challenge recognising that the impact of dementia on the nation was enormous both presently and as forecast into the future. The Prime Minister's Challenge set out a national programme of action to:

1. Deliver sustained improvements in health and care;
2. Create dementia friendly communities;
3. Boost dementia research.

In November 2013 the Department of Health published a report on dementia care and support in England¹⁴. This report looked at the quality of care and support for people living with dementia and concluded that, “The very best services are excellent and show what is possible. But the worst show that we still have some way to go. The message is clear: we can and must do better.”

Also in November the national Dementia Action Alliance launched The Carers Call to Action (CC2A) which asked organisations to commit to some fundamental actions that would improve the care and support available to carers (see section 12, Support for carers).

In June 2014 the All Party Parliamentary Group published their latest report - *Building on the National Dementia Strategy: Change, progress and priorities*¹⁷, which was produced after considering a previous review that had looked at the national Dementia Strategy (2009). This report focused on three key areas:

- Diagnosis and post diagnosis support
- Commissioning
- Workforce

A number of recommendations were made and it specifically referred to the fact that the national Dementia Strategy had come to the end of its expected life (2014) and therefore the recommendations it has made are of particular interest. Those recommendations have been repeated in this Strategy (and appropriately attributed) as they are as much of a priority in Medway as they are nationally.

There is a local political connection with the APPG Dementia Report as one of the vice-chairs is Tracey Crouch MP, Chatham and Aylesford.

At the time of writing, The Alzheimer’s Society published an overview of the findings of research that it had commissioned⁽²³⁾. The full report will be issued toward the end of 2014 and aims to provide ‘an accurate understanding of dementia prevalence and cost in the UK to assist in policy development, influencing, commissioning and service design’ (Alzheimer’s Society, 2014).

Action 2

The publication of the second edition of Dementia UK by Alzheimer’s Society later in 2014 will need to be taken into account as the Implementation Plan continues to develop.

6. Needs Identified in Medway

Key to the Dementia Strategy is the need to develop a greater community awareness and understanding of dementia illnesses and the effect dementia has on people's lives as well as the importance of focusing on 'living well with dementia' and developing earliest possible interventions. The development of a local Dementia Action Alliance will help greatly in developing wider and deeper community awareness and understanding of dementia.

Joint work is continuing to support the ongoing Public Health England Dementia Friends Campaign. Dementia Friends Champions are being trained in Medway in order that Dementia Friends sessions can be delivered throughout local communities.

Greater awareness and understanding will help to tackle issues of stigma and encourage people to support each other at the beginning of a person's journey with the condition. The Alzheimer's Society 'don't bottle it up' campaign is encouraging people to talk to their GP about any concerns that they might have.

Projected service use and outcomes in 3–5 years and 5–10 years

The most significant challenge with respect to the provision of dementia care is the increase in the ageing population over the next 20 years. The graph below illustrates the expected growth.

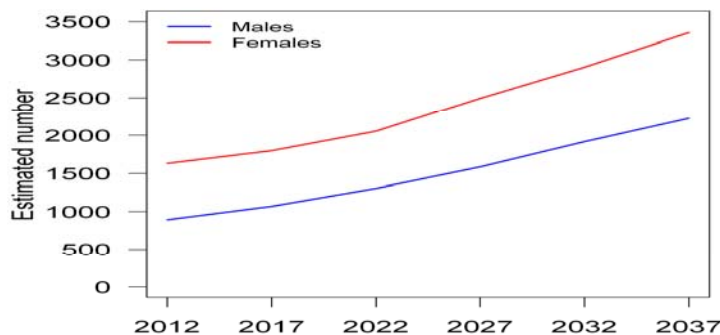


Figure 3: Trends in estimated number of people living in Medway with Dementia aged 65 years and over^[6]

	Females	Males	Persons
2012	1,629	893	2,522
2017	1,798	1,068	2,866
2022	2,056	1,304	3,360
2027	2,495	1,583	4,078
2032	2,904	1,916	4,820
2037	3,359	2,224	5,583

Table 6: Trends in estimated number of people living in Medway with Dementia aged 65 years and over [6]. Please note, figures may not sum due to rounding

Notes: Age-sex prevalence estimates have been taken from Dementia UK 2007 report produced for the Alzheimer's society by King's College London and the London School of Economics. The prevalence rates have been applied to ONS population projections of the 65 and over population to give estimated numbers of people predicted to have dementia.

Between 2012 and 2037, the number of older people living in Medway with Dementia is expected to increase from approximately 2,500 to 5,600. This is driven by projected changes in the age structure of the population.

Using the information in previous sections the proportions of the population expected to have mild, moderate or severe dementia the following table illustrates the expected changes over the next 25 years.

	2012	2017	2022	2027	2032	2037
Mild	1,387	1,576	1,848	2,243	2,651	3,071
Moderate	807	917	1,075	1,305	1,542	1,787
Severe	328	373	437	530	627	726
Total	2,522	2,866	3,360	4,078	4,820	5,583

Table 7: Trends in estimated number of people living in Medway with Dementia aged 65 years and over by level of severity [6][3]

Notes: These predictions are based on prevalence rates in a report by Eric Emerson and Chris Hatton of the Institute for Health Research, Lancaster University, entitled Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England, June 2004. The authors

take the prevalence base rates and adjust these rates to take account of ethnicity (i.e. the increased prevalence of learning disabilities in South Asian communities) and of mortality (i.e. both increased survival rates of young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities). Therefore, figures are based on an estimate of prevalence across the national population; locally this will produce an over-estimate in communities with a low South Asian community, and an under-estimate in communities with a high South Asian community.

This means there will also be an increase in the number of older people with learning disabilities which will also affect the need for services

Unmet needs and service gaps

1. Between 2012 and 2037, the number of older people living in Medway with Dementia is expected to increase from approximately 2,500 to 5,600. This is driven by projected changes in the age structure of the population. This will represent a huge challenge as current services will have to nearly double in capacity if in their present form or different approaches will need to be found. 45% of these people will be likely to have moderate to severe dementia.
2. The development of a clearly described integrated care pathway for dementia would assist both people living with the condition and professionals supporting people to access services without increasing the stresses and anxieties already likely to be present in people's lives.
3. Current under-reporting in primary care, which is an issue nationally, and the variation in the quality of dementia care in primary care needs to be addressed to improve early diagnosis and intervention.
4. Improving professional understanding and appropriate management of dementia is an ongoing need. This is the case for all health and social care professionals, including doctors, care staff and acute hospital staff.
5. There is still stigma associated with dementia which means that people may be reluctant to seek help for themselves or their loved ones. Further campaigns (e.g. Dementia Friends) to change public perception and reinforce the importance of early diagnosis need to be supported locally.
6. 24/7 practical support to carers needs to be further developed to ensure that people living with dementia are supported to remain in their own homes for as long as possible and for any admissions to acute settings to be as short as possible.

Action 3

Community awareness of dementia will be developed by continuing to support national Dementia Awareness campaigns such as the ongoing Public Health England Dementia Friends initiative which is being promoted by Alzheimer's Society and endorsed by the Prime Minister.

The Dementia Strategy recognises the importance and benefit of developing a greater understanding of dementia illnesses and the challenges that people living with dementia face on a daily basis. It is agreed that a local dementia action alliance will be established to support greater understanding by bringing the community of Medway together to work collectively on common aims.

7. A Whole Community Challenge

The challenge of dementia is not solely a health and social care one. It is a challenge that the whole community of Medway faces and action in response to this challenge will be undertaken by the community as a whole. To support the notion of developing Medway as a dementia friendly community the Alzheimer Society's initiative of formulating a local Dementia Action Alliance (DAA) is being supported through the developing strategy. The DAA becomes the vehicle by which the community as a whole can successfully become a dementia friendly community.

The DAA is owned and driven by its component members and whilst the Strategy and commissioning options will support and facilitate the creation of the DAA, sustaining it becomes the responsibility of the DAA itself.

A dementia-friendly community is one in which people with dementia are empowered to have aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them. Many villages, towns and cities are already taking steps towards becoming dementia-friendly communities. One area that has successfully utilised this model is Motherwell in Scotland. It has involved working with shop assistants, public service workers, religious groups, businesses, police, transport and community leaders. Outcomes have been positive and include a range of activities undertaken to increase community awareness of dementia including; promotional materials being distributed widely throughout the town, a successful Football Memories event held at Motherwell FC, awareness sessions with local fire fighters, Training of police officers and arrangement with Boots to distribute Alzheimer Scotland helpline cards.

The Dementia Action Alliance website describes the difference between these different elements:

What is the difference between a Dementia Action Alliance and a Dementia Friendly Community?

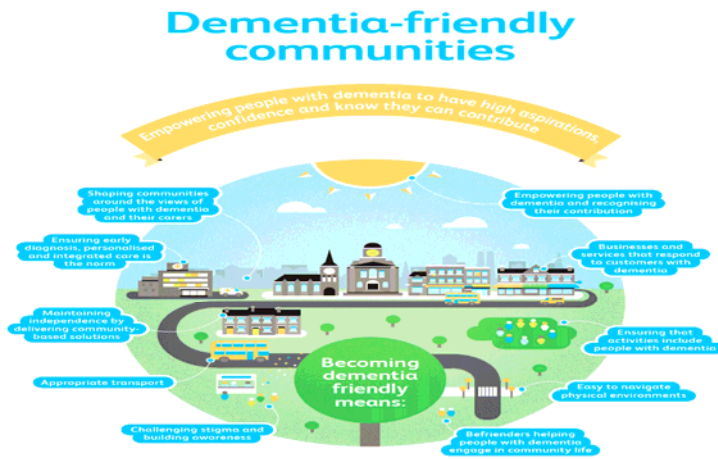
'Local Dementia Action Alliances' **enable** 'Dementia Friendly Communities'.

Therefore Local Dementia Action Alliances are about **action** via member organisations and communities committing to improve the lives of people with dementia and their carers.

A Dementia Friendly Community and being awarded the 'Working to become Dementia Friendly' symbol is about **recognition**.

The Dementia Friends initiative is a **practical example** of raising awareness of dementia. It is a good starting point for individuals, organisations and members of Local Dementia Action Alliances to take part in.

The key to understanding the challenge of dementia as a whole community challenge is to see the solutions that can be generated when a community works together:



Infographic from Alzheimer's Society (2014)

Action 4

A local dementia action alliance will be created as a vehicle to bring the community of Medway together. Organisations will be asked to create individual action plans as well as agree together a common set of aims. The alliance creates an opportunity for relationships between people and organisations to grow and develop into action that will change and improve the quality of life for people living with dementia.

Medway Council and Medway CCG have commissioned a one year pilot project for the Alzheimer's Society to set up and develop the Alliance.

8. Commissioning for Quality and Safety

The Strategy will set out commissioning intentions which will ensure focus remains on delivering services that are safe, efficient and effective and deliver the best outcomes. Clear specifications and contracts will be agreed and monitored to ensure that a clear focus on quality and outcomes can be demonstrated throughout the duration of activity.

- The aims of the Dementia Strategy take into account the growing needs within the Medway population and in recognition of changing priorities within health and social care. The Dementia Strategy will inform commissioning activity on behalf of both Adult Social Care and the CCG.
- Public awareness about dementia and its effect on people's lives should be the focus of attention within the community of Medway and the creation and support of a local Dementia Action Alliance is seen as the most effective way of becoming a dementia friendly community.
- The role of the GP is central to meeting people's needs and there will need to be a continued development of understanding for the importance of early diagnosis, treatment through medication, and the care and support that is available through social care services including those provided by the independent sector.
- The role and importance of the 'carer' will be incorporated into the Strategy and supported by the commissioning options selected for implementation. Priority will be given to ensuring that services are available to avoid and manage crises that may lead to avoidable hospital or care home admissions.
- The Dementia Strategy Implementation Plan will set out in the form of clear pathways the journey that people with a developing dementia disease are expected to take. Together with clear pathways there is a need to develop clear information, guidance and support that can be understood and available in easy to understand formats. Options being considered for practitioner and patient signposting will continue to be explored.
- A dementia friendly community will enable people living with dementia to live in a way that promotes a sense of value and ability to make a continued meaningful contribution to the community. The strategy has been developed from an understanding of the needs and aspirations heard from listening carefully to people living with dementia, both the person with the condition and their carers.
- To ensure services provide quality at each point on a person's dementia journey, support and development will be necessary within the care home sector.

Action 5

This Strategy supports the recommendation of the All-Part Parliamentary Group's report – Building on the National Dementia Strategy: Change, progress and priorities:

Every CCG and local authority should appoint a Dementia Lead with specific responsibility to ensure high-quality dementia services.

When planning and commissioning services, CCGs and local authorities, should:

- **use evidence**
- **assess local dementia needs**
- **engage with people affected by dementia and use their personal stories**
- **share data effectively and safely**
- **consider dementia services in applications for the Better Care Fund.**

There is a need for a major culture shift to improve the status and morale, both perceived and experienced, in care work to ensure it is an attractive and fulfilling career choice.

Services will be commissioned to ensure good quality of service, as well as cost-effectiveness.

9. Clinical Perspective

The development of the Strategy is being driven through the local health and social care partnership that incorporates clinical leadership and links with regional clinical networks such as the Dementia Fellowship Programme and the South East Coast Strategic Clinical Network Group (incorporating both the Dementia Commissioners Forum and the Dementia Clinical Advisory Group).

There are no drug treatments available that can provide a cure for Alzheimer's disease. Although there are medicines have been developed that can improve symptoms, or temporarily slow down their progression¹⁰. Medicines will not be effective for all individuals though. The brains of people with Alzheimer's disease show a loss of nerve cells that use a chemical called acetylcholine as a chemical messenger. The loss of these nerve cells is related to the severity of symptoms that people experience. Drugs such as Donepezil, Rivastigmine and Galantamine may temporarily improve or stabilise the symptoms of Alzheimer's disease.

An increasing number of non-pharmacological therapies are now available for people with dementia. These include standard therapies such as behavioural therapy, alternative therapies such as art or music therapy and brief psychotherapies such as cognitive behavioural therapy¹¹.

Each approach is rarely used in isolation, therefore, a combination of treatments tailored to the individual requirements of the patient may be necessary.

The Department of Health State of the Nation report on dementia care reports that:

“In July 2012, the National Dementia and Antipsychotic Prescribing Audit of 3,850 GP practices, covering 196,695 people with a diagnosis of dementia, reported a 52 per cent reduction in the prescribing of antipsychotic medication for people with dementia between 2006 and 2011.”¹⁴

The data in Table 8 below is for the quarter period March 2014 to May 2014 with the variance being measured against December 2013 to February 2014. When reviewing the data it is important to bear in mind that:

- This is a local monitoring initiative only as there is no national indicator for measuring the use of low dose antipsychotic usage in dementia
- Patient data will need to be reviewed to accurately determine if low dose antipsychotics are being used for behavioural problems in dementia as opposed to other indications such as psychoses etc
- The data is dependent on the quality of practices’ QOF recording

Area	Indicator	Achievement Range		NAT	WK CCG	DGS CCG	Med CCG	Swale CCG
Low-dose Antipsychotics in dementia	Low dose antipsychotic tag items - divide by patients on dementia reg x 1000 (New 2012/13 registers used)	NO targets This is to monitor increase in use		1,849	2,076	1,768	2,114	2,029
		Variance from last Quarter's report		12.6	3.0	-114.1	123.9	78.5

Table 8: NHS Medway CCG prescribing levels compared with national and local CCG levels

Action 6

Ensuring that initiatives are based on the best possible clinical research and evidence is critical. Through our Partnership Commissioning work we will continue to ensure that links are maintained locally, regionally and nationally with expert bodies.

Progress with the development of an audit process using Audit + (a clinical data audit and data analysis tool available to most GP Practices in Medway) will continue, together with the development of guidance and support to GPs to ensure that data collection for people with dementia including the use of anti-psychotic medication is as accurate and up to date as possible.

10. The Importance of Diagnosis

Nationally a great emphasis is being placed on the early diagnosis of dementia to ensure that people can be provided with treatment and interventions at the earliest possible opportunity. Greater community awareness of dementia and the benefit of early diagnosis will help to improve the diagnosis rate.

The flow of people through local memory assessment services is one area that is currently being assessed together with pre and post diagnostic support.

Obtaining an early diagnosis enables a person with dementia and their family to receive help in understanding and adjusting to the diagnosis and to prepare for the future in an appropriate way. This might include making legal and financial arrangements, changes to living arrangements, and finding out about aids and services that will enhance quality of life for people with dementia and their family and friends. Early diagnosis can allow the individual to have an active role in decision making and planning for the future while families can educate themselves about the disease and learn effective ways of interacting with the person with dementia. There is evidence that the currently available medications for Alzheimer's disease may be more beneficial if given early in the disease process¹⁰. These medications can help to maintain daily function and quality of life as well as stabilise cognitive decline in some people. Early diagnosis allows for prompt access to medications and medical attention.

Action 7

Medway Council and CCG will prioritise post-diagnostic support for people affected by dementia. This includes personalised advice, information and support, and ensuring that people with dementia know what to expect following a diagnosis.

The Better Care Fund will be an opportunity to integrate services in order to improve outcomes for people with dementia.

11. The Critical Role of the GP

The role of the GP in the success of a Dementia Strategy is critical. When a person with a developing dementia illness becomes concerned they will most likely approach their GP in the first instance. The GP's understanding of dementia, its effect on those living with it, the benefit of early diagnosis together are fundamental to ensuring that the journey a person makes starts off in the best possible way. The trust and confidence established between patient and GP is likely to dictate the quality of life a person experiences as their condition develops. GPs play a vital role not only in ensuring early diagnosis but in ensuring that well-planned and co-ordinated community services are in place to help people after diagnosis – this is part of the shared care model of patient focused care and support that will be further enhanced in Medway.

GPs have been supported to develop a greater understanding of dementia. Professor Sube Banerjee, Professor of Dementia & Associate Dean, Brighton and Sussex Medical School spoke to a meeting of Medway GPs in May 2014 about the importance of their role in tackling the challenge of dementia.

In July 2014 NHS England and Hardwick CCG, with the support of the Department of Health and Royal College of General Practitioners, published a latest edition of the publication 'Dementia Revealed – What Primary Care Needs to Know (A Primer for General Practice)' ⁽²²⁾. This GP guide aims to increase confidence in how GPs manage the challenge of dementia.

"Most GPs feel unprepared for the new focus on dementia ... There are some who still feel that making a diagnosis confers no benefit on patients because the ultimate outcome is not altered. This attitude is largely the result of being out of the loop with regard to dementia care." (NHS England, 2014)

At a meeting of Medway GPs on September 2014 GPs watched the Dementia Friends film and have been asked to become Dementia Friends and to promote this initiative within their practices. GPs were also consulted on this Strategy.

GPs are being supported to improve the rates of diagnosis for people living with dementia. New training approaches are being considered to support GPs to improve awareness and clinical skills in diagnosing dementia at a primary care level.

Action 8

The critical role of the GP is recognised and work will continue to support their greater understanding of dementia.

GPs will be supported to implement the guidance issued by NHS England in their 'primer for General Practice'.

GPs will be engaged further as the Implementation Plan develops to ensure that primary care is better able to meet the challenge of dementia.

12. Support for Carers

Better care for people living with dementia is about supporting people and their carers to live 'well' which means maintaining a person's familiar and cherished lifestyle for as long as possible. Where interventions are necessary these should be delivered sensitively and at an earliest point, with crises being managed effectively to avoid inappropriate disruptions to wellbeing arising from avoidable admissions into secondary care and/or care homes.

In 2012 the Prime Minister reported that "an estimated 21 million people in our country know a close friend or family member with dementia – that is 42 percent of the population."¹³

The report went on to state that there were an estimated 550,000 carers of people with dementia in England with an anticipation that one in three people are likely to care for a person with dementia at some point in their lifetime.

Supporting the carer in their enduring relationship with someone living with dementia is critical in sustaining people in their familiar lifestyles. Supporting carers through innovative schemes with the voluntary sector will be explored.

Public health campaigns will improve community understanding of dementia and assist with developing greater patient responsibility to 'choose well' when accessing services but it is the patient – GP relationship that remains key. Choices on the part of the patient and GP need to be made from an informed position and the availability and use of information is important.

GP signposting is a project being developed. Running across all areas of the Better Care Fund this project will enable GPs to access information about the care and support services that are available within local communities. The project has the potential to develop signposting initiatives that could also improve information available to patients as well as practitioners.

- Many carers of older people with dementia are themselves old
- Carers of people with dementia generally experience greater stress than carers of people with other kinds of need, nearly one-half having some kind of mental health problem themselves

The majority of people living with dementia live at home. Supporting carers' needs is essential if this situation is to continue, especially as the number of people with dementia increases.

The national Dementia Action Alliance initiative Carers Call to Action has gained widespread support and has established its commitment and shared vision as:

Carers of people with dementia:

- have recognition of their unique experience - 'given the character of the illness, people with dementia deserve and need special consideration... that meet their and their caregivers needs' (World Alzheimer Report 2013 Journey of Caring)
- are recognised as essential partners in care - valuing their knowledge and the support they provide to enable the person with dementia to live well
- have access to expertise in dementia care for personalised information, advice, support and co-ordination of care for the person with dementia
- have assessments and support to identify the on-going and changing needs to maintain their own health and well-being
- have confidence that they are able to access good quality care, support and respite services that are flexible, culturally appropriate, timely and provided by skilled staff for both the carer and the person for whom they care

DAA, 2014¹⁶

Action 9

It is agreed that the aims of the Carers Call to Action are supported and endorsed. A local dementia action alliance will promote the actions required to ensure these aims are achieved.

13. Earliest Interventions and Pathways

The various journeys a person living with dementia might make can be mapped and it is planned that clear pathways will be described for the first time making best use of initiatives such as Map of Medicine¹⁹.

What is apparent is that the same landscape is being described in different ways by different people.

Many people's journeys remain subject to confusion and a lack of clarity. One of the most significant comments made by people living with dementia and their advocates is the sense of not knowing what is happening. Pathways are being described through all dementia support services for both the person with a dementia illness and their carers including:

- Initial assessment
- Pre diagnosis support
- Diagnosis
- Post diagnosis support
- Adult social care (including support at home as well as accessing residential care options)
- Crisis support (including responses by emergency services)
- Continued primary care
- Accessing secondary care both planned and unplanned

Mapping services is being completed by seeking the views of both practitioners and users of services; through organised stakeholder events and accessing existing groups. Mapping will take into account services provided by health and social care agencies across all sectors.

The described pathways and the process to achieve these will identify:

- gaps in care and support services
- pressure points
- blockages
- aspirations

Action 10

Further work will be undertaken to set out the current pathways involved in dementia care, and to develop better ways to integrate these into a more seamless system. This will be the responsibility and focus for those commissioning services and will entail producing a commissioning model for dementia care that can be implemented from April 2015. This work will sit within the Better Care Fund framework to ensure its integration with other themes and strategic priorities set out by both the Council and CCG.

Current services:

Primary care

- The number estimated for the registered population for Medway CCG is 2,783. Data from the Quality and Outcomes Framework primary care dementia registers in 2012/13 have only identified 1,332 patients in Medway as having dementia. The estimated diagnosis rate for Medway CCG population is 47.87%, which is higher than the Kent and Medway average of

42.94% and the South of England average of 45.65%. The diagnosis rate has fewer than half of the population who are estimated to have dementia receiving a diagnosis. This could be due to a number of factors including late presentation and underdiagnoses. Nationally late diagnosis has been recognised as a problem and earlier diagnosis could be more cost effective in that it could slow progression of the disease and reduce costs. There are a number of actions being undertaken to improve the diagnosis rate. These include;

- (a) Medication analysis - using Audit + to identify patients who have been prescribed dementia medication but who do not have a recorded diagnosis
 - (b) Coding cleansing – based on work undertaken at Waltham Forest CCG to support GPs to identify problems in coding, which are contributing to low rates of dementia diagnosis on practice registers.
 - (c) Care Home Population analysis – Liaison with care homes to identify residents who clearly have dementia and liaise with practices to check that formal diagnoses have been made
- The central role of GPs is recognised in the Dementia Strategy and initiatives are being developed to develop a greater understanding and awareness of the importance of early diagnosis, treatment and providing patients and carers with meaningful information about care and support services that are available through the NHS, Adult Social Care and the independent sector.
 - An overriding approach adopted by the Dementia Strategy will see integration with the CCG's key clinical strategies and the priorities within the Better Care Fund. Knitting together the various strands that make up the community's complex needs is vital to ensuring those needs are met.
 - Statutory services are working together to ensure that the services they provide offer people a coherent pathway as their dementia illness develops and needs become more complex. Most people will approach their GP when they feel that something is not right and support is being provided to local Practices to help GPs and other professionals gain a better understanding of dementia and the importance of obtaining an early diagnosis.

Secondary care

- Medway NHS Foundation Trust have made dementia the focus of much work in the last year and opened the dedicated Bernard Unit to support people with dementia whilst they receive treatment. The Trust has also adopted the Butterfly scheme which allows people with memory impairments to request a person centred approach to their care – this operates throughout the hospital. In addition to these initiatives dementia awareness training for staff working in the hospital has also been given a priority. A Trust wide group meet every two months to look at what progress has been made to improve care and support to people with dementia.
- Kent and Medway NHS and Social Care Partnership Trust (KMPT) take referrals from GPs where there is an indication of a dementia disease and support people through an assessment process with both pre and post diagnostic counselling as part of their memory assessment service. This support is provided through a multi-disciplinary team which includes Admiral Nurses, who are mental health nurses that specialise in dementia. KMPT provides on-going support and guidance with the aim of working in a shared care approach with a person's GP.

KMPT host the Medway Community Engagement Forum (see appendix 6 for Terms of

Reference). This group aims to bring together professionals and groups to work together to improve services for people living with dementia.

Community care

- Current services to support people living with dementia are wide and varied but are not always known about and those that operate in one area may not be present in another. There are dementia cafes run by voluntary sector organisations that provide an opportunity for those people with dementia and their carers to come together in an informal setting for mutual support and guidance. Organisations such as the Alzheimer's Society, Age Concern, the Sunlight Trust and the Thursday Group provide valuable support by telephone and face to face to help people deal with daily lives that are affected by dementia.
- Medway Community Healthcare (MCH) provides community based services and is registered to run Darland House a specialist residential facility providing nursing care to older people with mental health needs which are predominantly associated with dementia. Darland House offers people with complex needs an opportunity for careful assessment and for care plans to be developed that will help people live with needs that are often felt as very challenging to less specialist facilities.
- Medway Community Healthcare (MCH) provides a Dementia Support Service with a multidisciplinary team led by an Admiral Nurse which responds to and works to prevent crises that might occur in people's homes where the main support for a person with dementia is being provided by a carer. It is the aim of the service to avoid, where possible and appropriate, an admission to hospital or care home. A move away from a familiar setting can be a highly traumatic experience which may exacerbate a decline in the person's wellbeing. Where a person is admitted to hospital it is important that where possible and appropriate that a return to home is arranged as early as possible and the hospital's new Integrated Discharge Team will work with the Dementia Support Service and Adult Social Care to ensure this is achieved.
- MCH are also overseeing a pilot scheme that employs two Carer Support Coordinators from Carers First, with one being based with the Dementia Support Service in the community and the other based with the Integrated Discharge Team at Medway Maritime Hospital. This scheme provides support to carers to reduce the risk of crisis leading to avoidable hospital admissions or to support an earliest possible discharge.
- Medway's Council for Voluntary Service has been commissioned by Medway Council to achieve the following outcomes in the local area: Capacity Building; Co-ordination, Networking and Engagement; Encouragement and Development of Volunteering; Representation; Information, Support and Training.
- A crisis support team has provided 24/7 support for people in dementia and their carers in the home when this support is needed and this has been an extension to the Dementia Support Service run by MCH. A review of the Dementia Support Service should be carried out together with ongoing monitoring to make a judgement about the benefit of enhancing the service through the continued provision of home carers who would work together with the specialist team from MCH.

Residential and Nursing care and support in care homes

- CQC research into the care and support provided in registered care homes (reported in 2013) found that "People with dementia living at care home postcodes are more likely to be

admitted to hospital multiple times and to be admitted to hospital for conditions which are potentially avoidable.”¹⁵

- Medway Community Healthcare (MCH) provide community based services and are registered to run Darland House a specialist residential facility providing nursing care to older people with mental health needs which are predominantly associated with dementia. Darland House offers people with complex needs an opportunity for thorough assessment and for care plans to be developed that will help people live with needs that are often felt as very challenging to less specialist facilities.
- In Medway, there are twelve independent sector nursing homes registered with the Care Quality Commission and most of these will support older people who have varying degrees of dementia. However, there are few dedicated nursing homes providing care to people with complex and often challenging needs arising from their dementia. A pilot scheme commissioned by NHS Medway CCG to support nursing homes will provide these homes with additional support through a multi-disciplinary team in the form of the Integrated Care Home Team model. The aim of this scheme is to support homes to achieve an equal and improved standard of care and reduction on secondary care services. Whilst this scheme is not solely aimed at improving dementia care, by its holistic approach it will undoubtedly do so.

Whilst it is clear that the best outcomes for people living with dementia can be obtained by supporting people to remain at home for some people the inevitable degenerative nature of dementia illnesses may result in a higher level of care and support being necessary. Whilst this is not a preferred option it should, when provided, be of the best quality where individual's preferences and histories are well understood and taken into account.

Acute inpatient care at Medway Foundation Trust

- A 24/7 A&E psychiatric liaison team is in place at Medway Maritime Hospital who are also able to support appropriate management of A&E attenders and inpatients with dementia. MFT and KMPT are currently developing a dementia pathway within the Enhancing Quality Programme. This will include appropriate screening on entry, during any stay and onward referral into dementia services and/or primary care or a return home with additional support services. The key element here is to ensure that the component parts of dementia care and support work together to ensure that potential patient pathways are easy to navigate.

End of Life

- Supporting people who have lived with dementia and who are now at the end of their life has been identified as an important element of service provision. There is a need to develop initiatives with Care Homes and other providers to ensure that quality of life and living well with dementia extends to the final moments of a person's life. Links have been made with the Wisdom Hospice (Medway Community Healthcare) and these will be developed to ensure that people are enabled to die in a place of their choice with the support they need to allow that to happen. The service includes beds, bereavement support, advice and psychosocial and family support to patients and families. MCH also provide community palliative care at home, as well as day hospice care.

The pilot of the Integrated Care Home Model will include enhancing end of life care within residential settings; initially with nursing homes.

The Social Care Institute for Excellence (SCIE)¹² has produced guidance on 'end of life care for

people with dementia living in care homes', Research Briefing 40 (May 2012). It is recommended that the guidance is taken into account to ensure that care home staff become more confident in supporting people to plan for end of life. This will inevitably necessitate enhanced training. Care homes will find the use of advanced care plan formats invaluable. A key element to supporting people at this stage is to ensure that as much as possible is known about the person's cultural and personal preferences.

Dementia-friendly technology

Through Medway Control Centre (MCC) Medway Council has developed a locally based 'telecare' system which it describes as:

"MCC operates, monitors and maintains approximately 5500 Telecare connections which has allowed people, who may have otherwise been heavily reliant on carers or admitted to residential care, to continue living in their own homes independently.

MCC work effectively with their partners in social care and health to ensure that appropriate Telecare solutions form part of individual care packages. We also have a solid client base with our private clients through providing a bespoke Telecare service, from comprehensive assessments, through to supply, installation and ongoing maintenance/support."

The Alzheimer's Society published a charter for Dementia-friendly technology in June 2014¹⁸ which has gained widespread support. Building on the work already undertaken by MCC there is an opportunity to maximise benefit through further use and development of technology.

The Dementia Strategy recommends the adoption of the Alzheimer's Society Dementia Friendly Technology Charter and specifically the following recommendations:

Action 11

The recommendations of the dementia-friendly technology charter are supported:

- **The right to a care assessment will always include a consideration for dementia-friendly technology.**
- **A single, simple to use and regularly updated online resource detailing dementia-friendly technology will be developed.**
- **Accessible and easy to find information that lists where dementia-friendly technology is available in the local area – including a link to the Charter.**

MCC will take into account the specific needs of people with dementia when developing care services that use technology.

Map of Medicine

Map of Medicine¹⁹ is a commercially developed product that has gained much interest within the NHS. It is a technological interface between GPs and improved patient care pathways. Using carefully considered Map Pathways which provide a clear description of an entire potential patient journey resulting from a specific clinical condition such as a dementia illness.

A company called iMPower has been commissioned to develop practitioner signposting applications and it is hoped that dementia care and support will be one of the first areas to

be developed utilising the work and enthusiasm that has already been generated through local engagement around the Map of Medicine.

Action 12

A local dementia action alliance will support and enhance the way in which agencies that provide services work together to form a coherent, safe and clear pathways for people whose needs develop as they live with the progressive effects of dementia.

That work continues to develop the Map of Medicine into a tool that provides GPs with a means of directing health and social care and support that will assist the development of clear pathways.

Close work is required to ensure the changes to health and social care structures assist the development of closer work between GPs, healthcare professionals and social care professionals.

14. Knitting Priorities Together

The aim of the pathways is to develop a process which clearly describes the integrated services and support across the health and social care landscape including primary care, secondary care, social services and the voluntary sector.

The Better Care Fund has eleven identified themes and the CCG has key initiatives arising from the five clinical strategies that closely align to the BCF themes. There is a need to ensure that the Dementia Strategy is interwoven within these areas reflecting the complex nature of need and the interdependencies in service provision.

Areas of significant importance for integration across health and social care are:

- urgent care
- community redesign
- intermediate care
- reablement
- end of life
- social isolation
- rapid response / crisis intervention

An example of integration across work streams is the involvement of Partnership Commissioning in the development of the CCG led pilot of an Integrated Care Home Team model.

The Dementia Action Alliance is designed to drive integration across the Medway community and to build on work across council functions where links have already been made or are planned.

Examples are:

- integrated transport (e.g. making a link to ensure that Arriva bus staff have a basic awareness in dementia)
- Housing (e.g. partnership working at the Housing seminar taking place on 23rd June)
- Telecare
- Schools services (promotion of dementia awareness at an intergenerational level)

The key to ensuring that activity is knitted together is the coherent implementation of the strategy. Partnership and working together are essential. Two potential models are shown below:

Model 1

Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support (Alzheimer's Scotland, September 2012)²⁰

"This report sets out an integrated and comprehensive, evidence-based approach to supporting people with dementia and their carers in the community."

The 8 pillars are:

- The Dementia Practice Coordinator
- Therapeutic interventions to tackle symptoms of the illness
- General health care and treatment
- Mental health care and treatment
- Personalised support
- Environment
- Community connections

Model 2

Healthcare at home has developed a model for out-of-hospital dementia care. It aims to deliver healthcare at home to deliver better outcomes for patients, at a lower cost and reduced hospital admissions and has been captured in their 2011 report specifically on dementia care.²¹

The Care Act

"Catering for the health and care needs of our growing and ageing population is a national priority. Reforming our care and support system is vital for us to be able to meet this challenge." (LGA, 2014)

The Care Act 2014 sets out a series of new functions that will be implemented from April 2015. The Act introduces new duties and responsibilities on local authorities with the aim of ensuring that local people:

- Receive services that prevent their care needs from becoming more serious, or delay the impact of their needs;

- Can get the information and advice they need to make good decisions about care and support;
- Have a range of high-quality care providers to choose from.

“The Local Government Association (LGA), Association of Directors and Adult Social Services (ADASS) and Department of Health are working in partnership to support local areas in implementation of the care and support reforms in the context of the other changes and challenges for local health and care systems, including the Better Care Fund.” (LGA, 2014)

Action 13

The Dementia Strategy will be taken into account when considering the ways in which the new Care Act duties and responsibilities will be implemented.

Action 14

The new Care Act duties to facilitate and shape the local market will be used to look at how local dementia care and support services can be commissioned to drive forward change that leads to a diverse and sustainable range of options for people in Medway.

15. Delivering on Equality

Dementia affects everyone in some way; either due to developing a dementia illness or by being affected as a carer, relative, friend or colleague. Dementia does not discriminate and it is prevalent amongst all sectors of the community. There are indications, however, that early onset dementia has a higher prevalence amongst people with Down’s Syndrome.

Further research is required in relation to the support and information needs of BME groups in relation to dementia and the resource implications of dementia prevalence in older people with a learning disability. Further research is also required around the dementia needs for people who identify as lesbian, gay, bisexual and transgender (LGBT).

Action 15

As part of the Implementation Plan further research will be undertaken within Medway to establish the effect of dementia on:

- **People from BME communities**
- **Those identifying as LGBT**
- **People with a learning disability**

16 Agreed Actions

Action 1

Medway residents and particularly those people who are living with dementia will be consulted on the Dementia Strategy. This will be a key aim of a local Dementia Action Alliance and will occur at regular intervals in recognition that the Strategy is a 'living breathing' document that needs to reflect the changing needs of the Community.

Healthwatch Medway will be asked to facilitate this consultation using their relationship with the Council and NHS as a 'critical friend'.

Action 2

The publication of the second edition of Dementia UK by Alzheimer's Society later in 2014 will need to be taken into account as the Implementation Plan continues to develop.

Action 3

Community awareness of dementia will be developed by continuing to support national Dementia Awareness campaigns such as the ongoing Public Health England Dementia Friends initiative which is being promoted by Alzheimer's Society and endorsed by the Prime Minister.

The Dementia Strategy recognises the importance and benefit of developing a greater understanding of dementia illnesses and the challenges that people living with dementia face on a daily basis. It is agreed that a local dementia action alliance is established to support greater understanding by bringing the community of Medway together to work collectively on common aims.

Action 4

A local dementia action alliance will be created as a vehicle to bring the community of Medway together. Organisations will be asked to create individual action plans as well as agree together a common set of aims. The alliance creates an opportunity for relationships between people and organisations to grow and develop into action that will change and improve the quality of life for people living with dementia.

Medway Council and Medway CCG have commissioned the Alzheimer's Society to co-ordinate this.

Action 5

This Strategy supports the recommendation of the All-Part Parliamentary Group's report – Building on the National Dementia Strategy: Change, progress and priorities:

Every CCG and local authority should appoint a Dementia Lead with specific responsibility to ensure high-quality dementia services.

When planning and commissioning services, CCGs and local authorities, should:

- use evidence
- assess local dementia needs
- engage with people affected by dementia and use their personal stories
- share data effectively and safely
- consider dementia services in applications for the Better Care Fund.

There is a need for a major culture shift to improve the status and morale, both perceived and experienced, in care work to ensure it is an attractive and fulfilling career choice.

Services will be commissioned to ensure good quality of service, as well as cost-effectiveness.

Action 6

Ensuring that initiatives are based on the best possible clinical research and evidence is critical. Through our Partnership Commissioning work we will continue to ensure that links are maintained locally, regionally and nationally with expert bodies.

Progress with the development of an audit process using Audit + (a clinical data audit and data analysis tool available to most GP Practices in Medway) will continue, together with the development of guidance and support to GPs to ensure that data collection for people with dementia including the use of anti-psychotic medication is as accurate and up to date as possible.

Action 7

Medway Council and CCG will prioritise post-diagnostic support for people affected by dementia. This includes personalised advice, information and support, and ensuring that people with dementia know what to expect following a diagnosis.

The Better Care Fund will be an opportunity to integrate services in order to improve outcomes for people with dementia.

Action 8

The critical role of the GP is recognised and work will continue to support their greater understanding of dementia.

GPs will be supported to implement the guidance issued by NHS England in their 'primer for General Practice'.

GPs will be engaged further as the Implementation Plan develops to ensure that primary care is better able to meet the challenge of dementia.

Recommendation 9

It is agreed that the aims of the Carers Call to Action are supported and endorsed. A local dementia action alliance will promote the actions required to ensure these aims are achieved.

Action 10

Further work will be undertaken to set out the current pathways involved in dementia care, and to develop better ways to integrate these into a more seamless system. This will be the responsibility and focus for those commissioning services and will entail producing a commissioning model for dementia care that can be implemented from April 2015. This work will sit within the Better Care Fund framework to ensure its integration with other themes and strategic priorities set out by both the Council and CCG.

Action 11

The recommendations of the dementia-friendly technology charter are supported:

- The right to a care assessment will always include a consideration for dementia-friendly technology.
- A single, simple to use and regularly updated online resource detailing dementia-friendly technology will be developed.
- Accessible and easy to find information that lists where dementia-friendly technology is available in the local area – including a link to the Charter.

MCC will take into account the specific needs of people with dementia when developing care services that use technology.

Action 12

A local dementia action alliance will support and enhance the way in which agencies that provide services work together to form a coherent, safe and clear pathways for people whose needs develop as they live with the progressive effects of dementia.

That work continues to develop the Map of Medicine into a tool that provides GPs with a means of directing health and social care and support that will assist the development of clear pathways.

Close work is required to ensure the changes to health and social care structures assist the development of closer work between GPs, healthcare professionals and social care professionals.

Action 13

The Dementia Strategy will be taken into account when considering the ways in which the new Care Act duties and responsibilities will be implemented.

Action 14

The new Care Act duties to facilitate and shape the local market will be used to look at how local dementia care and support services can be commissioned to drive forward change that leads to a diverse and sustainable range of options for people in Medway.

Action 15

As part of the Implementation Plan further research will be undertaken within Medway to establish the effect of dementia on:

- People from BME communities
- Those identifying as LGBT
- People with a learning disability

Appendix 1

Dementia Care & Support Organisations

Alzheimer's Society

Maidstone & Rural Communities Office
1 Dairy Court
Fair View Farm
Linton Road
Loose
Maidstone
Kent
ME15 0AL
Tel: 01622747181
Email: maidstone@alzheimers.org.uk

Community Mental Health Team for Older People

Elizabeth House
Holding Street
Rainham
Kent
ME8 7JP
01634382080
www.kmpt.nhs.uk

Thursday Group

St Stephens Church
Maidstone Road
Chatham
ME4 6JE

Medway Community Healthcare

7-8 Ambley Green
Gillingham Business Park
Gillingham
Kent
ME8 0NJ
Tel: 01634 382777

Medway Voluntary Action

Tel: 01634 812850
Email: enquiries@mva.org.uk

Age UK Medway

Tel: 01634 572616
Email: enquiries@ageukmedway.org.uk

Capstone Centre
Chatham
Tel: 01634 406058

Dementia Flexible Outreach Service
Tel: 01634 401099

Dementia UK

2nd Floor
Resource for London
356 Holloway Road
London
N7 6PA

The Wisdom Hospice

High Bank
Rochester
Kent
ME1 2NU
01634 830456
www.friendsofthewisdomhospice.org.uk

Medway Control Centre

Medway Council
Gun Wharf
Dock Road
Chatham
Kent
ME4 4TR
Tel: 01634 332091

The Sunlight Trust

105 Richmond Road
Gillingham
Kent
ME7 1LX
Tel: 01634 338600
Email: info@sunlighttrust.org.uk

Appendix 2

Consultation

Medway LiNK Research project	March 2012
Dementia Awareness Week Listening & Learning from Experience event	May 2014
Mental health provider and user forum	July 2014
Community Services stakeholder event	July 2014
Ad hoc meetings with people with dementia and their carers	March – September 2014
Medway GP's	September 2014
Medway Councillors	November 2014
Parish Councillors	
Internal Departments with Council e.g. leisure services	
CCG colleagues	
Social work teams	
Health and Social Care commissioners	
Public Health	
Medway Health Watch	
Medway Voluntary Action	
Wide range of voluntary sector organisations	

Appendix 3

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- 10 **Alzheimer's Society** (2011). Factsheet: Drug treatments for Alzheimer's Disease http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1760
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- 12 **SCIE**, Research Briefing 40, May 2012
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- 21 **Healthcare at Home**, Understanding out-of-hospital Dementia Care report, 2011
- 22 **NHS England**, Dementia Revealed – What Primary Care Needs to Know, July 2014
- 23 **Alzheimer’s Society**, Dementia UK second edition Overview, September 2014
- 24 **Department of Health**, Factsheet 1 – General responsibilities of local authorities, 2014

Appendix 4

Evidence of what works

Department of Health (2009) Living well with dementia: a national dementia strategy.

<https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>

This strategy provides a strategic framework within which local services can; deliver quality improvements to dementia services and address health inequalities relating to dementia; provide advice and guidance and support for health and social care commissioners and providers in the planning, development and monitoring of services provide a guide to the content of high-quality services for dementia.

Department of Health (2013)

Dementia: A state of the nation report on dementia care and support in England

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf

This Dementia report, with its accompanying map of variation, available at <http://dementiachallenge.dh.gov.uk/map/>, shines a light on the quality of dementia care in England. The very best services are excellent and show what is possible. But the worst show that we still have some way to go. The message is clear: we can and must do better.

Dementia Challenge (2012)

<http://dementiachallenge.dh.gov.uk/>

The Prime Minister's Dementia Challenge launched in March 2012. It sets out plans to go further and faster in improving dementia care, focusing on raising diagnosis rates and improving the skills and awareness needed to support people with dementia - and their carers. It also has details of plans to improve dementia research.

Dementia Partnerships (2012)

<http://dementiapartnerships.com/wp-content/uploads/sites/2/models-of-care-for-dementia.pdf>

Dr Edana Minghella, proposes a new understanding of the dementia journey and a revised model of care for dementia, aimed at improving experiences and outcomes, and informing service redesign and commissioning.

The Prime Minister's Challenge on Dementia (2012): delivering major improvements in dementia care and research by 2015: Annual report of progress

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200030/9535-TSO-2900951-PM_Challenge_Dementia_ACCESSIBLE.PDF

The progress of the Dementia Challenge is overseen by three groups of 'champions'. This is their latest progress report.

NICE/Social Care Institute for Excellence (2006) CG42 Dementia: supporting people with dementia and their carers in health and social care

<http://www.nice.org.uk/nicemedia/live/10998/30318/30318.pdf>

This guideline makes recommendations for the identification, treatment and care of people with dementia and the support of carers. Settings relevant to these processes include primary and secondary healthcare, and social care. Wherever possible and appropriate, agencies should work in an integrated way to maximise the benefit for people with dementia and their carers.

NICE (2010) End of life care for people with dementia: commissioning guide: implementing NICE guidance

<http://www.nice.org.uk/media/0A2/66/CommissioningGuideEoLDementia.pdf>

This commissioning guide has been developed to help support the local implementation of NICE clinical guidelines to commission integrated end of life care services for people with dementia. The guide makes the case for commissioning end of life care for people with dementia, highlighting key benefits.

NICE (2011) Dementia: care pathway.

<http://pathways.nice.org.uk/pathways/dementia>

This pathway covers supporting people with dementia and their carers in health and social care. It considers pharmacological and psychosocial interventions.

SCIE (2012) End of life care for people with dementia living in care homes

<http://www.scie.org.uk/publications/briefings/briefing40/>

This research briefing is about the care provided in care homes to people with dementia in the period leading up to the end of their lives. It aims to provide an overview of a range of issues important to care home residents, carers and providers.

Alzheimers Society (2011) Optimising treatment and care for people with behavioural and psychological symptoms of dementia

http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=609

This best practice guide was developed in consultation with an advisory group of leading clinicians specialising in dementia. It is aimed at a wide range of health and social care professionals caring for people with dementia who have behavioural and psychological symptoms to provide evidence-based support, advice and resources.

Dementia Partnerships (2014) Dementia: 10 key steps to improving timely diagnosis

<http://dementiapartnerships.com/10-key-steps-for-general-practice>

Living Well With Dementia In Medway

This Briefing is designed to support GPs and primary health care teams to improve the recognition, diagnosis and management of dementia.

Appendix 5

Registered Care Homes for older people

Care Home	Service type	Address	Postcode	Number of beds	Service type code	Speciality	Age
Abbeyfield – Rogers House	Residential	Drewery Drive Wigmore Gillingham Kent ME8 ONX	ME8 ONX	43	CHS	DE	65+
Acorn House	Residential	39 Maidstone Road Chatham Kent ME4 6DP	ME4 6DP	20	CHS		65+
Agape House	Residential	45 Maidstone Road Chatham Kent ME4 6DG	ME4 6DG	20	CHS	DE	65+
Amherst Court	Residential	Palmerstone Road Chatham Kent ME4 6LU	ME4 6LU	112	CHS	DE	65+
Amicus Residential Home	Residential	5 Hillside Avenue Frindsbury Strood Rochester Kent ME2 3DB	ME2 3DB	18	CHS		65+
Ampersand House	Residential	Parsonage Lane Frindsbury Strood Rochester Kent ME2 4HP	ME2 4HP	27	CHS	DE	65+
Aquarius Residential Home	Residential	8 Watson Avenue Chatham Kent ME5 9SH	ME5 9SH	20	CHS	DE	65+
Berengrove Park Nursing Home	Nursing Home	43-45 Park Avenue Gillingham Kent ME7 4AQ	ME7 4AQ	36	CHN	DE	65+
Byron Lodge Nursing Home	Nursing Home	105-107 Roack Avenue Gillingham Kent ME7 5PX	ME7 5PX	28	CHN		65+
Charing House	Residential and Nursing	Canterbury Street Gillingham Kent ME7 5AY	ME7 5AY	88	CHN	DE+LD +PD+SI	65+
Cherry Acre Residential Home	Residential	21 Berengrave Lane Rainham Gillingham Kent ME8 7LS	ME8 7LS	17	CHS	DE	65+
Chimnies Residential Home	Residential	Stoke Road Allhallows Rochester Kent ME3 9PD	ME3 9PD	29	CHS		65+
Clairmont Residential Home	Residential	89-91 Woodside Wigmore Gillingham Kent ME8 0PN	ME8 0PN	13	CHS	DE	
Copper Beeches Nursing Home	Nursing Home	5 Sylewood Road Cookham Wood Rochester Kent ME1 3LL	ME1 3LL	36	CHN	DE	65+
Durland House Residential Home	Residential	160 High Street Rainham Gillingham Kent ME8 8AT	ME8 8AT	13	CHS		65+
Fontenay Nursing Home	Nursing Home	39 Watts Avenue Rochester Kent ME1 1RZ	ME1 1RZ	27	CHN		65+
Fort Horsted Nursing Home	Nursing Home	Primrose Close Chatham Kent ME4 6HZ	ME4 6HZ	30	CHN		65+
Frindsbury Hall Nursing Home	Nursing Home	Frindsbury Hill Strood Rochester Kent ME2 4JS	ME2 4JS	74	CHN		65+
Friston House	Residential and Nursing	414 City Way Rochester Kent ME1 2BQ	ME1 2BQ	81	CHN	DE	65+
Grace Manor Nursing Home	Nursing Home	348 Grange Road Gillingham Kent ME7 2UD	ME7 2UD	60	CHN	DE+LD +PD+SI +substance misuse	+/-65
Grafton Lodge Residential Home	Residential	40 Goddington Road Strood Rochester Kent ME2 3DE	ME2 3DE	20	CHS		65+
Greenford Residential Home	Residential	260-262 Nelson Road Gillingham Kent ME7 4NA	ME7 4NA	18	CHS	DE	65+
Hawthorn Manor Residential Home	Residential	369 Maidstone Road Wigmore Gillingham Kent ME8 0HX	ME8 0HX	37	CHS		65+
Heather Dale Nursing Home	Nursing Home	204 Hempstead Road Hempstead Gillingham Kent ME7 3QG	ME7 3QG	37	CHN		65+
Holly Lodge Residential Home	Residential	208 Maidstone Road Chatham Kent ME4 6HS	ME4 6HS	22	CHS	DE	65+
Rose House		25 Railway Street Gillingham KENT me7 1XH	me7 1XH	18	CHS	DE+LD +PD	65+
Northmore Residential Home	Residential	77 Barnsole Road Gillingham Kent ME7 4EA	ME7 4EA	9	CHS	DE	65+
Park View Residential Home	Residential	Canterbury Street Gillingham Kent ME7 5AY	ME7 5AY	44	CHS	DE	+/-65

Living Well With Dementia In Medway

Pembroke House	Residential and Nursing	11 Oxford Road Gillingham Kent ME7 4BS	ME7 4BS	54	CHN		65+
Platters Farm Lodge	Respite and rehab only	Highfield Road Rainham Gillingham Kent ME8 0EQ	ME8 0EQ	43	CHS	DE	65+
Rochester Care Home (Robert Bean Lodge)	Residential	Pattens Lane Rochester Kent ME1 2QT	ME1 2QT	39	CHS	DE+M H+PD+ SI	65+
Shaws Wood (MDJ Homes) Residential Care	Residential	Mill Road Strood Rochester Kent ME2 3BU	ME2 3BU	36	CHS	DE	65+
The White House Residential Home	Residential	95-97 Maidstone Road Chatham Kent ME4 6HY	ME4 6HY	38	CHS	DE	65+
Valley View Nursing Home	Nursing Home	Maidstone Road Rochester Kent ME1 3LT	ME1 3LT	33	CHN		65+
Victory Care Home (Nelson court) Residential Home		Nelson Terrace Luton Chatham Kent ME5 7JZ	ME5 7JZ	39	CHS	DE+M H+PD+ SI	65+
Yew Tree Lodge Residential Home	Residential	Stoke Road Hoo Rochester Kent ME3 9BJ	ME3 9BJ	34	CHS		65+

Total beds	1313
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Appendix 6

Conclusion to the All-Party Parliamentary Group Report 2014 report – Building on the National Dementia Strategy: Change, progress and priorities

The APPG recommends a new, long-term dementia strategy, which incorporates our recommendations set out in this report, and involves people with dementia. This will be fundamental to the future of dementia care.

Five years on from the launch of the first ever National Dementia Strategy, the APPG on Dementia saw 2014 as an excellent opportunity to revisit our 2010 inquiry, 'A missed opportunity'. Given that so much has changed since this report was published and that the National Dementia Strategy has now come to an end, we have taken the opportunity to look forward and examine what needs to happen for people with dementia in the future.

Following discussions and engagement events with commissioners, providers, experts in the voluntary and private sector, and of course people with dementia and their families it is clear to us that the government must commit to a new long-term strategy for dementia. Such a strategy should be bold and ambitious to be a worthy successor to the NDSE and the Prime Minister's challenge on dementia.

In this review, we focused our attention on three important areas: diagnosis and post-diagnostic support; commissioning dementia services; and developing a skilled workforce. We found common themes running through all our discussions and our recommendations are based around these.

Strong leadership

Dementia needs strong leadership from government, from local authorities and CCGs, and from service providers, to ensure it is a priority in every service.

Integrated health and social care services

People with dementia have the most to gain from integrated services and now is the best time to start putting this into action. We want to see all commissioners using the opportunity that the Better Care Fund offers to promote more integration across health and social care, which needs to be extended beyond the current financial limitations of the fund.

Engaging and involving people with dementia

People with dementia and their carers should have a say on any decisions that could affect them. Wherever possible, people with dementia should play an integral part in commissioning, training and providing support to other people with dementia.

Finally, we recognise that there are many other issues that require attention, which will significantly improve the lives of people with dementia and their families, but which we haven't covered in this report. These include investment in research as well as making progress towards the creation of communities that are more dementia-friendly. Our primary aim for this report is to identify some priority areas for government and to urge it to commit to a long-term successor to the NDSE and Prime Minister's challenge.

'It is clear to us that the government must commit to a new long-term strategy for dementia. Such a strategy should be bold and ambitious to be a worthy successor to the NDSE and the Prime Minister's challenge on dementia'

Appendix 7



Medway Community Engagement Forum

Draft Terms of Reference

Purpose / objectives

- To foster collaborative working among mental health & social care service providers for older people with dementia in Medway.
- Improve communication between consumers and service providers & share good practice
- Inform and advice on gaps and service provision / commissioning
- Encourage community engagement & networking
- Help to improve user experience
- Support improving access and uptake of care provision for PWD & their families.
- Contributing to improvement & development of local services

Frequency: quarterly with accessible venues

Involvement: it was suggested that the group should involve & link up with other groups such as -
The Health & Wellbeing Board,
Clinical Commissioning Group (CCG)
Carer's Partnership Board.
Healthwatch England

Agenda: This will include:

- Organisation update on services
- Patient experience feedback
- Working together by sharing information & good practice
- Areas for improvement & development

Membership:

Statutory & non statutory organisations providing services for older people / Dementia in Medway.

Processing of monitoring compliance with ToR:

Review: This ToR will be reviewed yearly.

Appendix 8

Alzheimer's Society, Dementia UK second edition, Overview – Summary

This overview document provides an update on the figures presented in the first edition of Dementia UK (Alzheimer's Society, 2007). It is an overview of the full report, Dementia UK: Second edition, which will be published by Alzheimer's Society in autumn 2014. This document presents the best available evidence for the current cost and prevalence of dementia in the UK.

The full report was commissioned by Alzheimer's Society. It was researched and written by King's College London and London School of Economics in 2014.

Some of the key findings from the report are:

- The total age-standardised 65+ population prevalence of dementia is 7.1% (based on 2013 data).
- This equals one in every 79 (1.3%) of the entire UK population, and 1 in every 14 of the population aged 65 years and over.
- At the current estimated rate of prevalence, there will be 850,000 people with dementia in the UK in 2015.
- Compared to the 2007 estimates, the current prevalence consensus estimates are slightly higher for the youngest (65 to 69) and oldest (90+) age bands and slightly lower for the intermediate age groups (80–89).
- The total number of people with dementia in the UK would increase to over 1 million by 2025 and over 2 million by 2051 if age-specific prevalence remains stable, and increases are only driven by demographic ageing.
- This is a worst-case scenario. Improvements to education standards, cardiovascular health, activity levels and other known risk factors may all help reduce dementia incidence and prevalence in the future. However, available research in this area is not sufficient to allow us to forecast this in our current projections.
- There are over 40,000 people with early-onset dementia (under the age of 65 years) in the UK.
- The total cost of dementia to society in the UK is £26.3 billion, with an average cost of £32, 250 per person.
 - £4.3 billion is spent on healthcare costs.
 - £10.3 billion is spent on social care (publicly and privately funded).
 - £11.6 billion is contributed by the work of unpaid carers of people with dementia.

