

By: Graham Gibbens, Cabinet Member for Adult Social Care and Public Health

Andrew Ireland, Corporate Director, Social Care, Health and Wellbeing

To: Adult Social Care and Health Cabinet Committee – 6 December 2016

Subject: **DEMENTIA SERVICES – PROJECTS AND INITIATIVES**

Classification: Unrestricted

Previous Pathway of Paper: N/A

Future Pathway of Paper: N/A

Electoral Divisions: All

Summary: This report will update the Adult Social Care and Health Cabinet Committee on the various Dementia Services, Projects and Initiatives across Kent, including how these relate to the Prime Minister’s Dementia Challenge 2020 and how work across Kent is contributing towards achieving the aspiration contained with the challenge and the obligations of the Care Act.

Recommendations: The Adult Social Care and Health Cabinet Committee is asked to **COMMENT** on the progress made in supporting people living with Dementia and their Carers, **CONSIDER** and **COMMENT** on the content of this report and **ENDORSE** the approach of working with the NHS through the next stage of the Adult Social Care Transformation Programme to ensure Dementia services in Kent are of a high quality and consistently available.

1. Introduction

- 1.1 The Council has shown its commitment to supporting people who lives are affected by Dementia through all relevant key strategic documents. ***Increasing Opportunities, Improving Outcomes: Kent County Council’s Strategic Statement 2015 – 2020.***
- 1.2 Strategic Outcome 3 is that older and vulnerable residents are safe and supported with choices to live independently. This outcome is met through the following supporting outcomes:

- Those with long-term conditions are supported to manage their conditions through access to good quality care and support
- People with mental health issues and Dementia are assessed and treated earlier and are supported to live well
- Families and Carers of vulnerable and older people have access to the advice, information and support they need
- Older and vulnerable residents feel socially included
- More people receive quality care at home avoiding unnecessary admissions to hospital and care homes
- The health and social care system works together to deliver high quality community services
- Residents have greater choice and control over the health and social care services they receive

1.3 The Joint Health and Wellbeing Strategy contains a Dementia specific outcome, which is that people with Dementia are assessed and treated earlier, and are supported to 'live well'. The four priority areas being:

- Tackle areas where Kent is performing worse than the England average
- Tackle Health inequalities
- Tackle the gaps in provision and quality
- Transform services to improve outcomes, patient experience and value for money

1.4 The Council is committed to supporting Kent to be an inclusive and accessible place where people can live well with Dementia. Through the development of the Dementia Friendly Kent Programme and the Kent Dementia Action Alliance, a public commitment has been made to help improve awareness and understanding within Kent communities to ensure we are working together to make Kent more 'Dementia-Friendly'.

1.5 Ensuring Kent is more 'Dementia Friendly' is part of the Council's commitment to support people to have **a life and not a service**. People have repeatedly reported that they want to continue with hobbies and interests they had prior to diagnosis for as long as possible, services are important but so is being able to continue to live your life your way.

1.6 The Council provides and commissions a wide range of services and support for people living with Dementia and their Carers. Some services are Dementia specific but others such as Home Care and Kent Enablement at Home are generic services with staff trained to work with people with many different Long Term Conditions, including Dementia.

2. What is Dementia?

2.1 Dementia is a clinical syndrome of deterioration in mental function which interferes with activities of daily living.

- 2.2 Dementia affects more than one cognitive domain for example memory, language, orientation, or judgement and social behaviour for example, emotional control or motivation.
- 2.3 Early or young onset Dementia is generally defined as Dementia that develops before 65 years of age.
- 2.4 The most common subtypes of Dementia include:
 - 50-75% of people with Alzheimer's disease may also co-exist with vascular dementia
 - Vascular dementia up to 20%
 - Dementia with Lewy bodies 10–15%
 - Frontotemporal Dementia 2%
- 2.5 Modification of specific risk factors in particular, cardiovascular risk factors such as smoking, diabetes and lack of physical activity can delay or prevent the onset of Dementia.
- 2.6 Early diagnosis of Dementia is important for treatment of reversible causes and advance planning while a person still has mental capacity.

3. Prevalence Nationally and Locally

- 3.1 There are estimated to be around 800,000 people with Dementia in the UK. This includes 676,000 people with Dementia in England. By 2040, the number of people with the condition is expected to double. Dementia is very uncommon under the age of 65 with only one case for every 3,500 people. One in 68 people aged 70-74 are diagnosed with the disease, growing to one in 13 aged 80-84 and almost one in five people aged 90+.¹ Observed prevalence of recorded Dementia in England by age group and gender can be seen in Appendix 1.
- 3.2 In Kent approximately 20,813 people aged over 65 are estimated to have Dementia based on 2013-14 estimates. By 2017 it is predicted that this figure will increase to 21,991 (Kent Public Health Observatory Jan 2015).
- 3.3 Figures from NHS England for September 2016 show that 12,719 people in Kent (excl. Medway) have received a Dementia diagnosis. This is on average 62% of the estimated prevalence figure, up from 57.5% in 2014/15 and 44.3% in 2013/14. The NHS's national target for diagnosis is 67%. NHS England's figures per Clinical Commissioning Group (CCG) area can be found as Appendix 2.

4. Making Kent a more Dementia Friendly Place

- 4.1 The Prime Ministers Dementia Challenge was first launched in March 2012.

¹Dementia: policy, services and statistics. Number 7007, 17 October 2016

4.2 To ensure that Dementia remains a national priority the former Prime Minister revised his original challenge. Building on the considerable work already achieved he wanted work taken to the next level and by 2020 wanted England to be:

- the best country in the world for Dementia care and support and for people with Dementia, their Carers and families to live; and
- the best place in the world to undertake research into Dementia and other neurodegenerative diseases.

4.3 Central to this vision is ensuring that people with Dementia live in a society where they are able to say:

- I have personal choice and control over the decisions that affect me.
- I know that services are designed around me, my needs and my carer's needs
- I have support that helps me live my life
- I have the knowledge to get what I need
- I live in an enabling and supportive environment where I feel valued and understood
- I have a sense of belonging and of being a valued part of family, community and civic life
- I am confident my end of life wishes will be respected. I can expect a good death
- I know that there is research going on which will deliver a better life for people with Dementia, and I know how I can contribute to it.

4.4 In response to the Prime Minister's Challenge and a KCC Select Committee that considered Dementia and a Kent Dementia Friendly Communities (DFC) Programme was developed. The DFC began in May 2013 and the Programme consists of four work streams

1. Establishment Dementia Action Alliances
2. Encouraging Dementia Friendly Communities
3. Promoting Intergenerational Work and
4. The creation of Dementia Champions and Dementia Friends

4.5 We have developed a countywide Dementia Action Alliance with eight further local Dementia Action Alliances, including a specific Cultural Arm. Local Alliances bring together people who want to help improve the lives of people with Dementia in their area. They are seen as the local vehicle to develop Dementia Friendly Communities.

4.6 Across Kent there are fourteen communities registered as working towards becoming Dementia Friendly with a number of new communities in the process of starting up and applying for recognition. These groups each have their own local priorities however each group has also adopted the three priorities of the Kent Dementia Action Alliance which are:

1. Raising Awareness

2. Support Intergenerational Work and
3. Reducing Loneliness and Isolation

- 4.7 The Kent Model of Dementia Action Alliances and Dementia Friendly Communities has been recognised as good practice and has been adopted and promoted by the Alzheimer’s Society nationally, the model is attached as Appendix 3.
- 4.8 A comprehensive list of the work going on across Kent to meet the aspirations of the Prime Ministers Challenge can be found as Appendix 4.

5. Dementia Performance Information Referrals, Assessments and Services

5.1 The following information is based on data extracted from the Adult Social Services client data base SWIFT/AIS, and is for a 12 month period (Nov 2015 - Oct 2016) for Contacts, Referrals and Assessment. Service information is based on current open services as at October 2016. It is important to note that people will only be recorded on SWIFT/AIS as having Dementia if the case manager has been notified of a formal diagnosis, if the case manager suspect the person may have Dementia but does not have a diagnosis they will refer to the memory service for assessments. Therefore, we believe the number of people support who are living with Dementia is likely to be underrepresented in the data below.

5.2 Number of Referrals

Referral Reason	No. of Referrals where person has Dementia	Total referrals	% of Referrals where client has Dementia
Assessment Request	1,208	24,839	4.9%

5.3 Number of Assessments

5.3.1 Please note that assessments data also captures reviews, as these are classified as a re-assessment of need.

Assessments Completed relates to	No. of Completed Assessments	% of Assessments Completed
Person has Dementia	2,092	6.4%
Person does not have Dementia	30,548	93.6%
Total	32,640	100%

5.4 Number of People Receiving Support Services

Individual Receiving Support	No. of Individuals	% of Individuals
Person has Dementia	4,363	11.7%

Person does not have Dementia	33,020	88.3%
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5.5 Number and Type of Services Received

Service Type	No. of Services where Person has Dementia	Total Services	% of Services where Person has Dementia
Adult Placement Scheme	14	493	2.8%
Residential Care Home	2,785	10,375	26.8%
Direct Payment	675	7,254	9.3%
Home Care	1,115	17,063	6.5%
Equipment/Adaptation	365	13,852	2.6%
Nursing Care Home	854	2,519	33.9%
Telecare	420	7,430	5.7%
Grand Total	6,228	58,986	12.5%

6. Services and Support for People Living with Dementia and their Families/Carers

- 6.1 **Dementia Specific Information and Advice** – The Council has commissioned a 24hr Dementia Helpline to offer practical and emotional support. The helpline supports, on average, 50 families per month helping them with a sympathetic and well trained listening ear, access relevant help and support across Kent. The majority of each month's contacts are new contacts rather than repeat callers. Over the last six months 55% of callers have been female and 45% male. These can be further broke down to: 25% from a spouse, 32% from a daughter /daughter in law, 16% from an unknown connection, 10% from a son / son in law, and 6% each from friends, neighbours and professionals and 4% calling on their own behalf.
- 6.2 **Dementia Friendly Kent Website** - holds a variety of different information about events, activities, services and projects across the county. The website has been seeing a steady increase of visitors and over the last six months from May 2016 has averaged at over 900 visitors per month with between 25-30% of these being new visitors.
- 6.3 **Dementia Cafés** - The Council has funded Dementia Cafés in 25 areas across the county, a majority of these hosts two sessions per week. Cafés are a social place where people can meet for mutual support and also have access to information. Many Cafés have entertainment and ensure that they get a variety of speakers from different organisations to help keep people informed about the support available for them. In the last six month period (April 2016 to September 2016) a total of 228 sessions took place with an average of 17 people attending per session. These sessions are open to the person diagnosed and family/Carers, with attendance showing 44% attendees with a diagnosis, 51% a family carer and 4% declaring as other.

- 6.4 **Dementia Peer Support Groups** – The Peer Support Groups offer specific sessions for the person diagnosed with dementia and are a forum where people in the early to middle stages of their illness can meet and share experiences and offer mutual advice and support. In the last six month period (April 2016 to September 2016) a total of 102 sessions took place with an average of seven people attending per session.
- 6.5 **Social Opportunities/Day Services** - working from the ethos of ‘A Life not a Service’ it has been recognised that people affected by Dementia want to remain an active part of their community for as long as practicable. With that in mind, although a number of services need to be specific for people with Dementia in the latter stages, in the earlier stages of a person’s Dementia the stimulation and support provided by general social opportunities is a valuable commodity.
- 6.5.1 The Council funds a range of social opportunities/day services through grants to organisations such as Age UK, Alzheimer’s Society and Alzheimer’s and Dementia Support Services across Kent, who offer a range of services including Dementia specific day care for those who need a more intensive support.
- 6.5.2 The Council also has a number of in house provisions for Dementia Day Care. Blackburn lodge in Swale has three sessions of Dementia suitable day care per week, providing up to 45 places for people with Dementia. Gravesham Place, Westbrook House, West View and Broadmeadow all provide similar services.
- 6.6 **Tele-Technology** - in order to promote independence, reduce isolation and allow people to remain active within their community the Council is encouraging the use of tele-technology and has invested in ‘Just Checking’ a system to remotely monitor people’s activity and ensure accurate management of risk and the tailoring of care and support. The Council has also invested in GPS trackers and as of 30 September 2016, 52 GPS locator devices have been issued. These trackers allow people the freedom to leave home and provide Carers with peace of mind that people’s whereabouts can be monitored. The Council is working closely with Kent Police, Kent Fire and Rescue and Kent Search and Rescue to ensure effective policies and protocols for supporting people at risk of going missing are in place.
- 6.7 **Advocacy Service** – The new advocacy service has been developed to provide a greater understanding of the complexities of living with Dementia when dealing with issues of consent and best interest. The county wide advocacy service works with the Alzheimer’s and Dementia Support service to provide Dementia specific assistance for those who need an advocacy service. In the six month period from April 2016 to September 2016, 236 people with Dementia have been supported through the new advocacy contract.
- 6.8 **Mental Capacity Act** - 180 people living with Dementia were supported through Independent Mental Capacity Advocacy (IMCA) involvement in Care Reviews, Serious Medical Treatment and Safeguarding. 106 people living with Dementia were supported through the Deprivation of Liberty (DOLS) process.

128 people living with Dementia were supported through DOLS Paid Relevant Persons Representatives, eight of these cases involved Relevant Persons Representative support for Court of Protection Cases.

- 6.9 **Dementia Outreach Workers** - The Alzheimer's and Dementia Support Service, The Alzheimer's Society, Age UK Herne Bay, Age UK Deal and Age UK Faversham are funded to provide Dementia support to local residents through Dementia support workers. Dementia support workers provide support, information and guidance to people with Dementia and their Carers helping to maintain their independence, improving their sense of well-being and putting them in more control of their lives and to assist people with Dementia and their Carers to identify their needs and access to services.
- 6.10 **Alzheimer's and Dementia Support Services (ADSS)** - (covering the Dartford, Gravesham and Swanley area of Kent) provide dementia day care and Dementia support services. Figures provided show that over the six month period April 2016 to September 2016 ADSS have worked with on average 306 clients per month. This figure includes 615 new contacts, 56 clients who are exiting their services, 595 contacts signposted to additional services and have on average 3 people on a waiting list at any one time. These figures include contact into the Kent Dementia helpline which ADSS manage.
- 6.11 **Alzheimer's Society** - (covering a large proportion of East and South West Kent) provide Dementia day care and Dementia support services. Figures provided show that over the six month period April 2016 to September 2016 the Alzheimer's Society has worked with on average 412 clients per month. This figure includes 260 new contacts, 179 clients who are exiting their services, 179 clients who are signposted on to other services and have on average 20 people on their waiting list at any time.
- 6.12 **Support for Carers – Carers' Assessments and Carers Short Breaks Services.** Figures submitted for April 2016 to September 2016 show 647 Carers' Assessments made for Carers of those with Dementia, 108 one off Direct Payments made and 32 dementia specific Carers' activities sessions. The Carers Short Breaks preventative service show 534 clients have received in total 18,332 hours support.
- 6.13 **Crossroads Care Kent** - is also funded to provide other Dementia specific Carers' support services and the last six months figures show 80 people have attended Cognitive Stimulation Groups (COGS) totalling 6500 hours of support, 60 people have engaged with their Dementia outreach service receiving 600 hours of support and 30 people living with Dementia have received peer support totalling 600 hours.
- 6.14 **Age UK and Age Concern** - provide Dementia specific services in many areas of Kent and people living with Dementia often access the full range of non-specific services offered by these organisations.
- 6.15 **Emergency Support and Crisis Prevention** – The Council has jointly commissioned, with all seven Kent Clinical Commissioning Groups (CCG), a

Dementia and Carer Crisis Service designed to support people at times of crisis to prevent hospital or care home admissions and to support timely safe discharges from hospital. Through this joint funding, the last six month period April 2016 to September 2016 has seen:

- Short Breaks Service - 258 clients received in total 9330 hours of support
- Carer Health Appointments 97 clients in total receiving 827 hours of support
- Crisis Service 202 clients receiving 9077 hours of support

7. Projects developed through the Dementia Friendly Community (DFC) Programme

7.1 In addition to commissioned services there are a number of local services supported and initiated through the DFC programme. These include a large range of community led Dementia cafes which are run by volunteers:

- Tenterden Railway Station Café
- Westerham Forget me not Café
- Edenbridge Forget me not Café
- Rosie's Moments Dementia Café (Folkestone)
- Cranbrook- Memory Lane Café (Coming Soon)

7.2 For the last two years the DFC Programme has been awarding small innovation grants, £2,000 is available for each District/Borough annually. Projects must be linked to a local Dementia Action Alliance and must be developed and delivered by a partnership. A list of the grants awarded can be found in Appendix 5. More information can be found on the www.dementiafriendlykent.org.uk website.

7.3 The DFC programme has been championing and developing the ***Working to Become Dementia Friendly*** recognition. Detail of all the businesses and organisations signed up will soon be published on the Dementia Friendly Kent Website. A 'draft' information sheet about the recognition symbol can be viewed in Appendix 6.

7.4 Promoting Awareness and information is one of the prime aims of the Dementia Friendly Community work. This year, during Dementia Awareness Week, Kent hosted a large range of events. Information about this year's Dementia Awareness Week events can be found in Appendix 7

8. Your life, your well-being - Draft Vision and Strategy for Adult Social Care 2016 - 2021

8.1 The Council has recently completed formal consultation on a new vision for adult social care, the aim of which is to help people to improve or maintain their well-being and to live as independently as possible. The Strategy breaks down the Council's approach to adult social care into three themes that cover the

whole range of services provided for people living with Dementia and their Carers:

1. **Promoting well-being** – supporting and encouraging people to look after their health and well-being to avoid or delay them needing adult social care
2. **Promoting independence** – providing short-term support so that people are then able to carry on with their lives as independently as possible
3. **Supporting independence** – for people who need ongoing social care support, helping them to live the life they want to live, in their own homes where possible, and do as much for themselves as they can

9 Dementia with Sustainability and Transformation Plans (STPs)

9.1 Prof Alistair Burn, National Clinical Director for Dementia, NHS England, has recently written to all Local Authorities and CCGs, stating

*“We propose a bold **transformation** of the way in which the needs of people with Dementia and their Carers are addressed by the health and social services with an emphasis on **prevention** (both primary prevention and avoiding additional disability due to co morbid conditions), **maintaining independence** for people with Dementia in their communities (specifically avoiding unnecessary hospital admissions) and providing **high quality support** for families and Carers. The overall aim is for the efficiencies to lead to **sustainable high quality care**”.*

9.2 Dementia is one of the key aspects of STPs, within Mental Health, and is one of the “must dos” with specific mentions of maintaining the national diagnosis rate at two thirds, tackling variation between CCGs and improving the provision of post diagnostic treatment and support.

10 Key Challenges

10.1 **Staff Recruitment and Retention** - although much has been and continues to be done to improve the support offered to people living with Dementia and their families/Carers, there are still significant challenges in recruiting sufficient workforce to work in some key services, especially home care provision in more affluent and rural areas.

10.2 **Improving Access to Information** - despite having invested in Dementia specific information and advice services, too often people do not know what is available or how to access it. The Council is working with NHS colleagues to develop a post diagnostic pathway that supports people to access the right support for them following their diagnosis.

10.3 **Ensuring High Quality Care and Support in all Settings** - improving and getting a more consistent approach to the training for key staff to develop skills in working with people with Dementia to prevent issues escalating and

behaviour becoming challenging. Through the DFC options for a special ***Working Towards Become Dementia Friendly*** training accreditation are being explored.

10.4 **Reducing Stigma and Improving Awareness** – on-going work is necessary to help reduce the stigma surrounding Dementia. NHS services being delivered under Mental Health rather than as a Long Term Condition, can influence public perception. Public perception can still be that people with Dementia should be in care homes there is a need to spread the message that people can live well with Dementia and want to be in their own homes for as long as possible.

11. Conclusion

11.1 Although there is a good range and variety of Dementia services across Kent, with some excellent examples of innovation and quality care, there is not a core or consistent offer.

11.2 Services have developed over time rather than being strategically commissioned. Through the next phase of the Adult Social Care Transformation Programme we will be working with a wide range of stakeholders, including people living with Dementia and their Carers to design new models of support. This will entail working in partnership with the NHS and ensuring more equitable access to services.

12. Recommendations

12.1 Recommendations: The Adult Social Care and Health Cabinet Committee is asked to **COMMENT** on the progress made in supporting people living with Dementia and their Carers, **CONSIDER** and **COMMENT** on the content of this report and **ENDORSE** the approach of working with the NHS through the next stage of the Adult Social Care Transformation Programme to ensure Dementia services in Kent are of a high quality and consistently available.

13. Background Documents

Increasing Opportunities, Improving Outcomes: Kent County Council's Strategic Statement 2015-2020

<http://www.kent.gov.uk/about-the-council/strategies-and-policies/corporate-policies/increasing-opportunities-improving-outcomes>

Joint health and wellbeing strategy

<http://www.kent.gov.uk/social-care-and-health/health/health-policies/joint-health-and-wellbeing-strategy>

Dementia: policy, services and statistics. Number 7007, 17 October 2016

<http://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN07007>

The Prime Ministers Dementia Challenge

<https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>

14. Lead Officers

Tracey Schneider

Project Officer, Dementia Friendly Communities

03000 415483

tracey.schneider@kent.gov.uk

Emma Hanson

Head of Strategic Commissioning, Community Support

03000 415342

emma.hanson@kent.gov.uk

Relevant Directors

Mark Lobban

Director of Commissioning

03000 415393

mark.lobban@kent.gov.uk

Anne Tidmarsh

Director, Older People and Physical Disability

03000 415521

Anne.tidmarsh@kent.gov.uk