HEALTH AND SOCIAL CARE
OVERVIEW AND SCRUTINY COMMITTEE

23 AUGUST 2016

ADULT SOCIAL CARE
DEMENTIA REVIEW

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Summary

This report provides an update on progress achieved on the Dementia Review since the last report was presented to Health and Social Care Overview and Scrutiny in January 2016.

The report sets out the opportunities and challenges which have emerged during the intervening period, and makes a number of recommendations for next steps. Among these, the key proposal is for the development of a 'Test for Change' pilot site for integrated, improved dementia care and support, located and designed around Health and Wellbeing Centres in Medway, as part of a phased approach to achieving full service redesign and implementation across the borough by 2020.

1. Budget and Policy Framework

1.1 The scope of the report is within the Council's policy and budget framework, and links closely with the forthcoming Members Task Group, investigating 'How far has Medway come in developing a Dementia Friendly Community?'

2. Background

2.1 In January 2016, a report was presented to Health and Adult Social Care Overview and Scrutiny Committee, setting out the progress since the publication of Medway's Dementia Strategy in 2015. The report provided an overview of the subsequent needs and gap analysis, and outlined priorities for action going forward. The broad strategic shifts required were described as follows:

Where we are now	Where we need to be
Commissioning based on traditional menu of service categories / types	Engaging with market to stimulate diversity, with innovative approaches to contracting for flexible support.
Persistent sense that no benefit in providing a diagnosis	Focus on supporting people to come to terms with and plan for the future.
Post-diagnostic support based in secondary care	Emphasis on community based support.
Care driven by needs and demands of services	Care / support designed around needs / contributions of people with dementia and carers.

2.2 An action plan set out the programme of activity, which was judged as being required in order to deliver these outcomes. A revised version of this action plan is reproduced as an appendix to this paper, updated to show progress made in the intervening period [See Appendix 1].

2.3 A significant part of the work has involved sourcing data and information at a more granular level, mapping out interfaces, engaging the relevant stakeholders and identifying key opportunities for improvement across the system. This has brought a number of issues to light:

- People with dementia (but another primary reason for admission) are significantly more likely to be affected by delayed transfers of care from hospital than are people without dementia. Of those with dementia, a significant proportion are originally admitted to hospital for apparently avoidable reasons (see Appendix 2 for analysis).

- There are a number of voluntary sector groups which provide important – even essential - support for people with dementia and their carers. Many do not receive any funding from Medway CCG or Medway Council at present, but they do play a critical role in existing care pathways (see Appendix for a recently completed evaluation of some of these services).

- Some targeted clinical support is provided to care homes locally (by both KMPT and MCH), but there is evidence of a fragmented approach.

- More broadly, care services for people with dementia are characterised by critical interfaces and interdependencies across the system. Priority areas which clearly require a whole system focus are:

    - Improving dementia diagnosis
    - Urgent care pathway for dementia patients
    - Support for care homes
    - Post-diagnostic community support

- Attempts to identify levels of investment in dementia services have proved challenging, due to the fact that funding is tied up in wider block contracts. There are no immediate plans to fundamentally change the provision for assessment and diagnosis, and attempts to disaggregate other aspects of

provision (e.g. for post-diagnostic support) in the medium term could have a destabilising effect on the wider system. As a result, there is still no defined funding envelope within which to locate this review, with its current whole system, Medway-wide scope (as set out in the previous report to Overview and Scrutiny in January 2016).

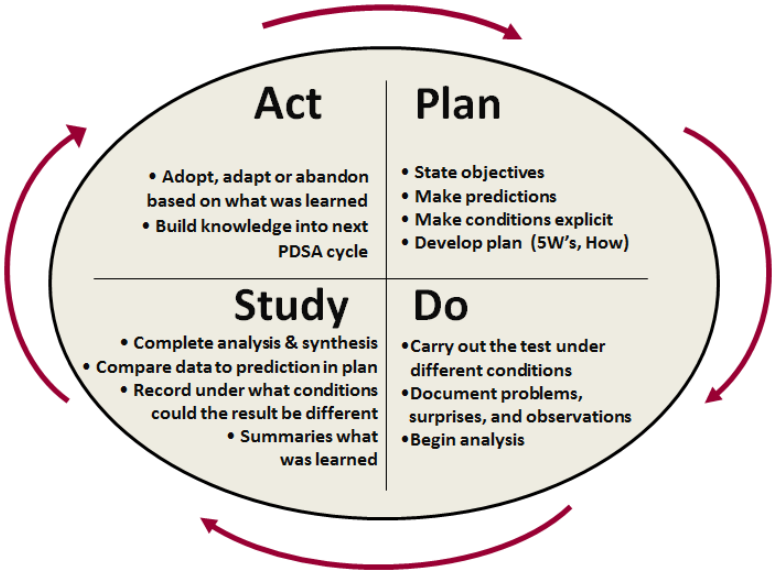
2.4 A further development is that a Members' Task Group has been launched, investigating 'How far has Medway come in becoming a dementia friendly community?' This illustrates the critical role of 'dementia friendly communities' in ensuring that care pathways are based on an understanding of the role of the wider community in enabling people with dementia to live well. This is also recognised by Medway's Dementia Action Alliance, which is a key partner in the wider dementia review[1].

2.5 The Members' Task Group is due to begin in mid-late summer 2016. In order to enable a strong input into the process of transformation, it would be beneficial to timetable any developments to enable the Members' Task Group, through their findings, to inform the direction of travel.

2.6 Therefore, for all of the reasons set out above, this report does not present a fully costed, mapped out plan for future Medway-wide service redesign.

2.7 At the same time, there remains a strong consensus around the direction of travel and the outcomes which people with dementia and their carers need to see, as summarised in the 'Key Strategic Shifts' table above.

2.8 As a consequence of the analysis outlined above, it is proposed that next steps be based on a 'Test for Change' approach. The principle is that small-scale tests of change can help determine whether an idea could result in sustainable improvement, prior to system wide commitment to a particular model. Changes can be tested under multiple conditions and with a variety of staff before being implemented. This approach is illustrated below.

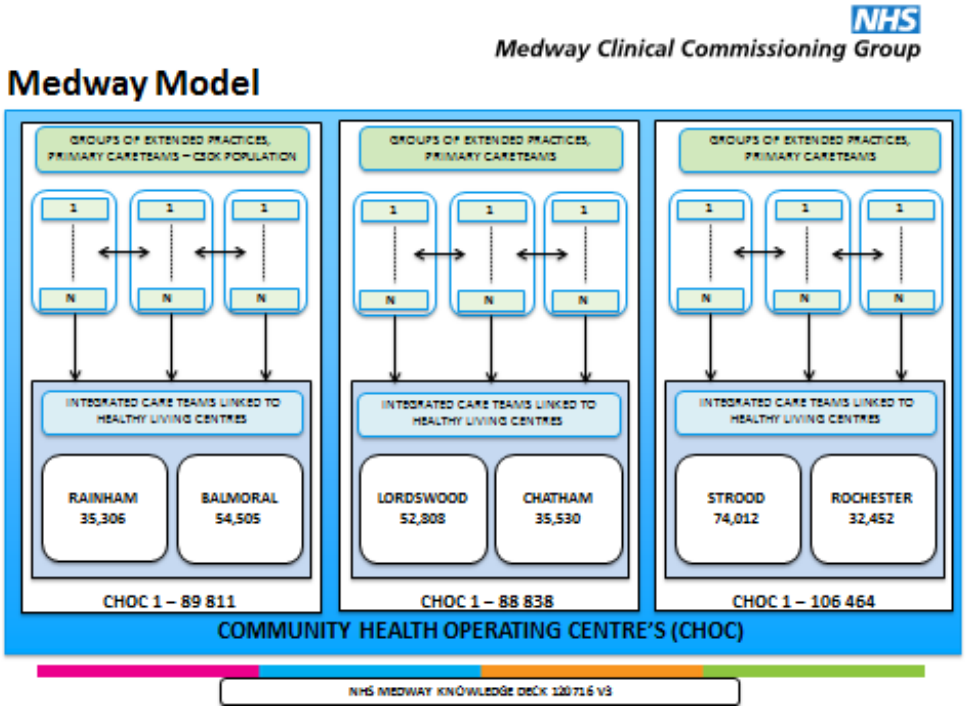


[1] The DAA has been jointly funded by Medway Council and CCG for calendar years 2015 and 2016.

2.9 It is proposed that a new integrated, community based model should be developed, and tested out, with a focus on (initially) one Integrated Care Team area. Initial discussions have taken place with a view to locating this first testing phase within the Rainham Health Centre, where the GPs are keen to work with the CCG and the Council to test out a new approach[2].

2.10 This offers the exciting prospect of a 'hub' model being developed at a local level, as part of a wider focus on Rainham as a dementia friendly community (informed by the Members Task Group and the Dementia Action Alliance). The Health and Wellbeing Centre could be supported to become Medway's first fully 'Dementia Friendly' GP Practice (Appendix 3).

2.11 This approach, with integrated teams linked to Health and Wellbeing Centres, aligns well with current thinking around the future model for primary care in Medway:



2.12 The following timescale envisages that a phased rollout, as described above.

Action	Lead	Timescale
Members Task Group starts	Medway Council	Sept 2016
Establish GP Cluster Area	Medway CCG / Council	By Oct 2016
Establish Task and Finish Groups for key pathways	Medway CCG, Medway Council and GP leads	Aug – Oct 2016
Establish local Rainham coordination group	Medway CCG, Medway Council and GP leads	Nov 2016
Establish Rainham patients and carers advisory group	CCG, Council and GP leads, patients and carers	Nov 2016

2.1 [2] The 2011 Census showed that Rainham has one of the oldest age profiles in Medway, suggesting that Rainham is likely to experience a relatively high prevalence of dementia. Therefore Rainham is proposed as an ideal location for the first phase of this exercise.

Members Task Group produces final report / recommendations	Medway Council Democratic Services / Members	Jan 2017
Develop implementation plan – Phase 1	Local Rainham coordination group	Feb 2017
Full implementation of Test for Change – Phase 1	Local Rainham coordination group	April 2017
Evaluate Phase 1, and refine model	CCG / Council / clinical leads	Oct - Dec 2017
Roll out to Phase 2	Medway CCG / Council; GP clinical leads	Jan 2018
Evaluation of Phase 2 exercise	Medway CCG / Council, GP leads	Aug – Oct 2018
Develop full Medway Commissioning Plan	Medway CCG / Council	Nov – Dec 2018
Undertake procurement for full service redesign	Medway CCG / Council	Jan 2018 – Jan 2019
Full implementation of new model across Medway	Medway CCG / Council	April 2020

3. Options

3.1 Given that there is a clear commitment to improve outcomes for people with dementia and their families, as outlined above, continuing with the status quo is not judged to be an option. Therefore the viable options are considered below.

Option	**Benefits**	**Cons**
Option 1: Continue moving directly towards full service redesign of dementia post-diagnostic care and support services - the 'revolutionary' approach	• Potential faster route to change • Possibly more straightforward to achieve full redesign within existing resources	• Complexity of current system; many services affected • May take longer, due to contractual issues • No scope to test on small scale
Option 2: 'Test for Change' approach, with phased rollout of more integrated, community based, person centred model of dementia care and support, based around Healthy Living Centres / GP Clusters (starting with one Cluster in initial phase)	• Greater likelihood of success • Findings of Members Task group can influence design of new local model • Supports cost-effectiveness, due to evaluation before further development	• Possible longer trajectory for full rollout (though may not actually be the case, as above) • Potential 'double running' costs – in - year negotiations with providers to avoid extra costs to Council / CCG

4. Advice and analysis

4.1 It is advised that an evolutionary 'Test for Change' approach should be supported, as set out above. It is suggested that the benefits outweigh the risks, which can be mitigated, as set out in the risk assessment (see below).

4.2 It is argued that the impact of this direction of travel will be to advance equality and foster good relations within and between community groups (see DIA).

4.3 Key actions to avoid any potential negative impacts of change on minority groups and indeed more generally, would comprise:

- Careful planning, involving partners and clinical leads, to ensure continuity, and to ensure process of service redesign is based on evidence
- Accurate needs analysis, to be updated as new data emerges
- Meaningful engagement with people with dementia and families from a wide range of backgrounds, to ensure a fully co-produced approach

5. Risk management

5.1 Analysis of risks associated with Option 2 as set out in the options appraisal:

Risk	Description	Action to avoid or mitigate risk	Risk rating
Potential delay to full scale implementation of new care pathways	Evolutionary, phased approach may require longer timescale to deliver whole system change across Medway	Options Appraisal suggests risks of delay from Option 1 potentially greater. Careful planning to mitigate potential extra lead in time.	C3
Potential cost implications of setting up a pilot	Risk associated with setting up test for change model in one area, while continuing to operate status quo across Medway – possible additional cost pressures	Work with providers to identify local solutions. Due to innovative approach, possible scope to bid for external funding e.g. to support voluntary sector role	C2

6. Consultation

6.1 Consultation has been comprehensive and is ongoing, including:

- Regular visits to meet people with dementia and carers, to embed the perspective of people with dementia and their families in all thinking and planning activity.
- Membership of the Medway Dementia Action Alliance (DAA), with officers attending and contributing to meetings / events / forums.

- Membership of and regular attendance of the Medway Dementia Community Engagement Group, a provider forum involving most of the key partner organisations in Medway in this field.

- Programme Steering Group providing day to day strategic accountability.

7. Financial implications

7.1 It has not proved possible to easily disaggregate the funding envelope for dementia within key contracts i.e. with KMPT and MCH. Further, it is clear that there is no immediate appetite to fundamentally change the provision for assessment and diagnosis and that attempting to disaggregate other aspects could have a destabilising effect on wider service provision.

7.2 Should this proposal receive strategic and political support, commissioners and clinical partners will quantify the resource going into the local hub, enabling commissioners to build up a financial picture and understand any cost implications. Opportunities will need to be identified to reconfigure existing arrangements locally, without additional resource. If a need for new funding emerges, e.g. to enable a particularly innovative approach, commissioners will aim to pursue external funding opportunities.

8. Legal implications

8.1 The recommendations outlined in this paper relate to the CCG's duties and powers as set out in the Health and Social Care Act 2012.

8.2 The proposals also align with the Care Act 2014, with its emphasis on the importance of prevention, early intervention, and working with communities to maximize local capacity and resources in order to support people with care and support needs to live as independently as possible.

9. Recommendations

9.1 It is proposed that Health and Social Care Overview and Scrutiny Committee should support the following recommendations:

i. That the next steps of the Dementia Review should focus on a 'Test for Change' exercise located in Rainham Health Centre in Medway, This would represent Phase 1 of a longer planned programme of work.

ii. That the learning will lead to and shape the development of a whole system recommissioning plan for Medway, enabling full redesign by 2020.

iii. That Members have the opportunity to influence the development of future service design via the forthcoming Task Group.

iv. That the comments made by the Committee and subsequently by the Health and Wellbeing Board (upon presentation of the report on13 September), are provided for comment and approval via the appropriate CCG governance arrangements.

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Appendices

Appendix 1: Dementia Commissioning Action Plan, August 2016
Appendix 2: Medway Foundation Trust Data – Emergency Admissions
Appendix 3: Becoming a Dementia Friendly GP Practice
Appendix 4: Community-Based Early Intervention Support Services for People with Dementia in Medway Evidence Review 2016-2017

Background papers

Dementia Commissioning Plan and Needs / Gap Analysis - January 2016
Diversity Impact Assessment – Dementia Review, July 2016
National Prime Minister's Dementia Challenge 2020
National Dementia Declaration
Dementia Friendly GP Practices resource

Appendix 1

Dementia Commissioning Action Plan – August 2016

What	Description	Who	When
Members' Task Group starts	First meeting of Members' Task Group, identifying key lines of enquiry, scope and objectives	Members' Services, supported by officers across Council including from Children and Adults	Sept 2016
Establish Task and Finish Groups for key pathways	Key pathways to comprise: • Referrals into secondary care, assessment and diagnosis • Post diagnostic support • Crisis pathway • Support for care homes	Medway CCG, Medway Council and GP leads	Aug – Oct 2016
Establish Test for Change Phase 1 location	Confirm Test for Change Phase 1 location (current plan: Rainham Civic Health Centre)	Medway CCG, Medway Council and GP leads – presentation will be made to local GP Care Team meeting	October 2016
Establish local coordination group	This group should include patients, carers, as well as project leads and key providers	Medway CCG, Medway Council and GP leads	Nov 2016
Establish project patients and carers advisory group	Recruitment could initially be through existing Patient Participation Group, as well as other local people living with dementia and their families	CCG, Council and GP leads, patients and carers	Nov 2016
Members Task Group produces final report	Report is published containing key conclusions and recommendations	Medway Council Democratic Services / Members	January 2017

Appendix 1

What	Description	Who	When
Develop implementation plan – Phase 1	Plan for first phase of Test for Change model is developed	Local Rainham coordination group	Feb 2017
Full implementation of Test for Change – Phase 1	Implementation plan is delivered with a go-live date of April 2017	Local Rainham coordination group	April 2017
Evaluate Phase 1; refine model	Full evaluation enabling lessons to be learnt to inform Phase 2	CCG / Council / clinical leads	Oct - Dec 2017
Phase 2 Rollout	Test for Change exercise extended to second Civic Health Centre location	Medway CCG / Council; GP clinical leads	Jan 2018
Evaluation of Phase 2 exercise	Full evaluation enabling lessons to be learnt to inform full service redesign	Medway CCG / Council, GP leads	Aug – Oct 2018
Develop full Medway Commissioning Plan	Full service redesign plan based on lessons learnt from Test for Change process	Medway CCG / Council / GP leads	Nov – Dec 2018
Undertake procurement for full service redesign	Full year is allowed, enabling large scale re-procurement to take place if required (subject to outcomes of evaluation)	Medway CCG / Council	Jan 2018 – Jan 2019
Full implementation of new model across Medway	New services / care pathways in place and operating, as per service redesign	Medway CCG / Council / GP leads	April 2020

As set out in the original report (January 2016), any re-commissioning exercise will be subject to a number of fixed factors, including the current CCG contractual timetable, and will also be subject to interdependencies with other key strategic programmes of transformation and recommissioning exercises. Key Interdependencies include:

- Adult Social Care Strategy, personalisation agenda and Care Act Implementation programme
- Integrated Mental Health Strategy
- Wider service development / redesign involving the Healthy Living Centres and focused around the role of Primary Care
- Telecare Strategy
- Intermediate Care Strategy and progress with Home to Assess Pilot
- Better Care Fund Framework
- Partnership Commissioning Review of Carers Support
- Partnership Commissioning Review and planned procurement exercise for Information, Advice and Advocacy Services
- Palliative care / end of life services

Update on Previous Dementia Commissioning Action Plan (presented to Overview and Scrutiny, 26th January 2016)

What	Description	Who	When	August 2016 Update
Identify and implement a co design process with partners of a service configuration for Medway that reflects best use of available resources whilst promoting the best possible outcomes for people and families affected by dementia				
Establish partnership governance arrangements	Set up Steering Group comprising lead representatives from Council, CCG and other partners, to oversee implementation of this Action Plan, supported by working groups	High level leads from Council, Public Health, CCG, health providers, people with dementia and families, voluntary sector, and Dementia Action Alliance. Supported by commissioning working groups as needed	By mid-February 2016	Steering group and Provider Advisory Group in place; engagement with people w. dementia and families active and ongoing
Dementia Whole System Summit for Medway	Event for key stakeholders, to identify optimum model for future dementia services in Medway (including focus on personalisation / person-centred care)	Led by Partnership and CCG Commissioning. Including people with dementia / families, providers, social care, GPs, VCS, Dementia Action Alliance (DAA)	25th February 2016, Pembroke Court	Whole System Summit took place - clear outcomes identified
Agree success criteria	Establish an agreed set of outcomes to demonstrate delivery of effective, accessible, person-centred and evidence led services to the wider Medway community and people affected by dementia	Overseen by Dementia Steering Group, led by Council / CCG Commissioners with input from health and social care providers, people with dementia and families, and DAA	Mid March 2016	High level outcomes agreed based on National Dementia Declaration
Establish interface between Dementia Commissioning Intentions / Care Pathway review and the wider objective to support Medway to become a Dementia Friendly Community				**August 2016 Update**
Medway Council and Medway CCG to develop Action Plan(s) as formal members of the Dementia	DAA Action Plan(s) covering two angles: a) how service redesign will support the outcome of Medway becoming a dementia friendly community; and b), what Medway Council and Medway CCG will	Championed by Steering Group, Action Plan focused on adult social care actions to be developed by Partnership Commissioning	End March 2016	Action Plan for Medway Council adult social care submitted and accepted – Medway Council adult

What	Description	Who	When	August 2016 Update
Action Alliance	themselves do to support this outcome, both as employers, and as a provider / commissioner of universal services e.g. arts, libraries, sports, leisure, General Practice and so on			services is now a formal Member of the DAA and of its Steering Group
Role of DAA in supporting this work to be clarified and agreed	Opportunity to emphasise importance of building community capacity, maximising existing strengths in the community. DAA can add real value by helping to co-design future service models with this outcome in mind	Partnership between Steering Group and Dementia Action Alliance	End March 2016 (now ongoing)	Strong relationship with DAA – further scope to build on this via proposed local hub model
Establish a particular focus on personalisation throughout the programme of work				**August 2016 Update**
Identify potential opportunity to roll out Personal Health Budgets in this area	As part of care pathway redesign work, explore potential opportunity to rollout Personal Health Budgets to people with dementia (potentially people with complex health conditions alongside dementia)	Overseen by Dementia Steering Group, working closely with CCG Contracts Team	End March 2016. Interface with PHBs Action Plan for NHS England	Broader PHBs focus locally still under consideration - opportunities can be scoped once confirmed
Personalisation of Dementia Day Services	Significant transformation exercise complementing the wider Dementia Commissioning redesign work. Key links with Adult Social Care Strategy and Care Act implementation	Led by Partnership Commissioning.	2016/17 transformation exercise.	This forms part of the broader day services review currently under way
Establish detailed understanding of existing costs and pressures in the system. Identify opportunities for efficiencies / reinvestment and the potential role of the Better Care Fund.				**August 2016 Update**

What	Description	Who	When	August 2016 Update
Undertake detailed analysis of existing costs	Identify current expenditure on primary, community and secondary dementia health care services, and social care services	Overseen by Steering Group, led by Council and CCG Commissioners with input from health and social care providers	End March 2016	Extensive analysis including: 'As is' service profile / mapping strengths / potential duplication; analysis of delayed discharges for patients with dementia at hospital; analysis of flow through ASC Intake Team; evaluation of benefits from VCS dementia services locally. Not yet possible to disaggregate costs in KMPT / MCH contracts associated with post-diagnostic dementia care
Undertake detailed analysis of potential for efficiencies / reinvestment	Analyse system-wide pressures (e.g. on A&E or hospital discharge) and identify opportunities for efficiencies and reinvestment as a consequence of an improved ICP / model for dementia care	Overseen by Steering Group, led by Council and CCG Commissioners with input from health and social care providers	End April 2016	
Identify potential role for Better Care Fund	Identify and agree whether or not there is a role for BCF funding in ensuring implementation of the new model and how this work interfaces with BCF framework	Overseen by Steering Group, working with BCF lead	End April 2016	
Establish Integrated Care Pathways (ICPs) and information sharing protocols				**August 2016 Update**
Draft optimum ICPs for dementia care in Medway	Care pathway task and finish event with representation from key agencies – informed by dementia commissioning priorities	Led by Partnership and CCG Commissioning. Including people with dementia / families; and key agencies / partners across system	End April 2016	Due to data and cost analysis exercise being more complex than anticipated, detailed mapping of care pathways require further
Develop information sharing	Work with key partners to identify existing information sharing protocols, and ensure they are fit for	Overseen by Steering Group with input from working groups as needed	By end May 2016	

What	Description	Who	When	August 2016 Update
protocols, as needed	purpose in the future, undertaking redesign as needed			focused joint work, as do any requirements for information sharing protocols
Consult on draft ICPs /information sharing protocols	Complete draft ICP for consultation with wider partners / stakeholders. Include referral pathways	Overseen by Steering Group with input from working groups as needed	By end May 2016	
Seek Health and Wellbeing Board view on draft ICPs / service model	Take report to Health and Wellbeing Board to seek their input and feedback on draft ICPs and proposed service model for dementia care in Medway	Overseen by Steering Group with input from working groups (especially Partnership and CCG Commissioning)	June 2016	See above. It is proposed to begin this work at local level, as envisaged via 'Test for Change' exercise, designed around one Civic Health Centre area
Agree final ICP / implementation plan	Achieve sign off by Steering Group and JCMG. Develop steps towards full implementation	Overseen by Steering Group with input from working groups as needed	By end June 2016	
Identify contractual position of existing provision and agree detailed Procurement Plan to enable system redesign.				**August 2016 Update**
Undertake detailed analysis of contractual position	Identify timescales of existing contracts. Understand outcomes which will be required as a result of future procurement of dementia care services	Overseen by Steering Group working closely with CCG and Council Contracts / Category Management teams	By end June 2016	See above. It is proposed to negotiate redesign / reconfiguration with providers at local level, initially, as a likely lower risk / more constructive approach overall
Develop detailed procurement plan	Develop detailed procurement plan in order to support ICP and new model of services which has been agreed (as above)	Overseen by Steering Group working closely with CCG and Council Contracts / Category Management teams	By end July 2016	
Secure final strategic support for implementing the new ICP / Service Model / Procurement Plan.				**July 2016 Update**
Seek strategic support from HASC Overview and Scrutiny Committee	Take detailed implementation plan to Health and Adult Social Care Overview and Scrutiny Committee / Heath and Wellbeing Board	Steering Group	August 2016	Proposed timetable for re-procurement and rollout now revised (see main paper). Planned

What	Description	Who	When	August 2016 Update
				phased approach to service redesign, with full re-commissioning in 2019/2020, and full implementation by April 2020
Seek final sign-off from JCMG	Take detailed implementation plan to JCMG for CCG / Commissioning sign off	Steering Group	August 2016	

Appendix 2

Dementia Review
Medway Foundation Trust Patient Data – Emergency Admissions

Every secondary care provider in England is required to send a set of data files to the National Secondary Users Service (SUS). SUS is a single, comprehensive repository for healthcare data in England which enables a range or reporting and analyses to support the delivery of healthcare services. Dr Foster is an organisation that holds health care data and uses aggregated total numbers from SUS.

As part of the Dementia Review Medway Foundation Trust reports from SUS and Dr Foster were analysed.

Data on 12472 patients from Medway Maritime Hospital who were 49yrs and over was available for analysis. However, 282 records contained partial information.

1. Length of Stay

People with dementia (but with another primary reason for admission) are significantly more likely to be affected by delayed transfers of care from hospital. Data analysis shows on average a person with dementia spends 6 days longer in hospital than a person without dementia.

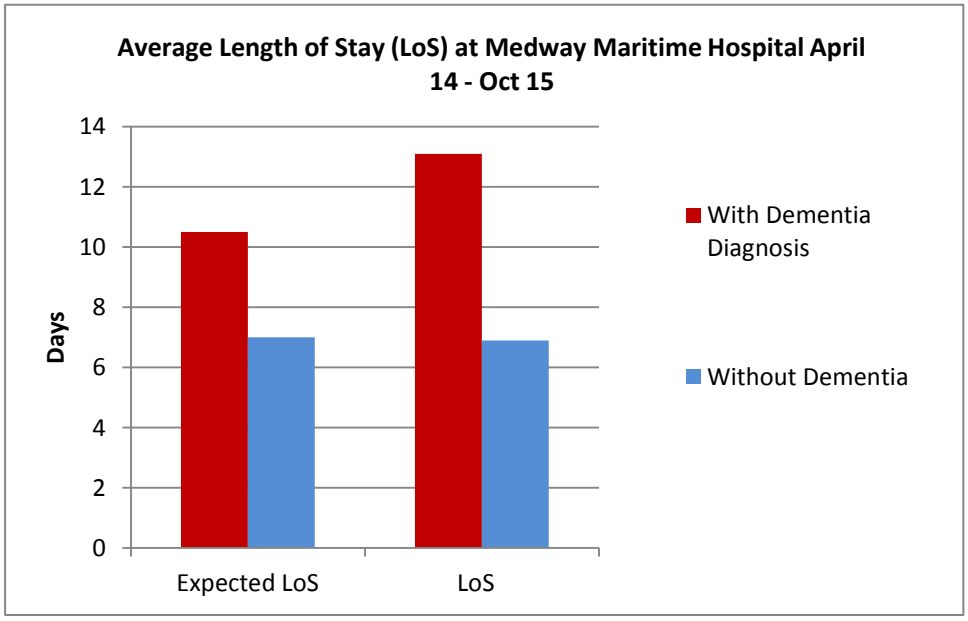

Chart 1: Average Length of Stay at Medway Maritime Hospital

Length of stay and admission reasons

165 medical reasons for admission were provided in the data. 44 of the 165 medical reasons for admission were shared by people with and without diagnosis of dementia.

Appendix 2

When analysing 44 shared conditions, 70% of conditions showed that people with a dementia diagnosis experienced a longer stay in hospital than people without dementia, see Chart 2.

Appendix 2

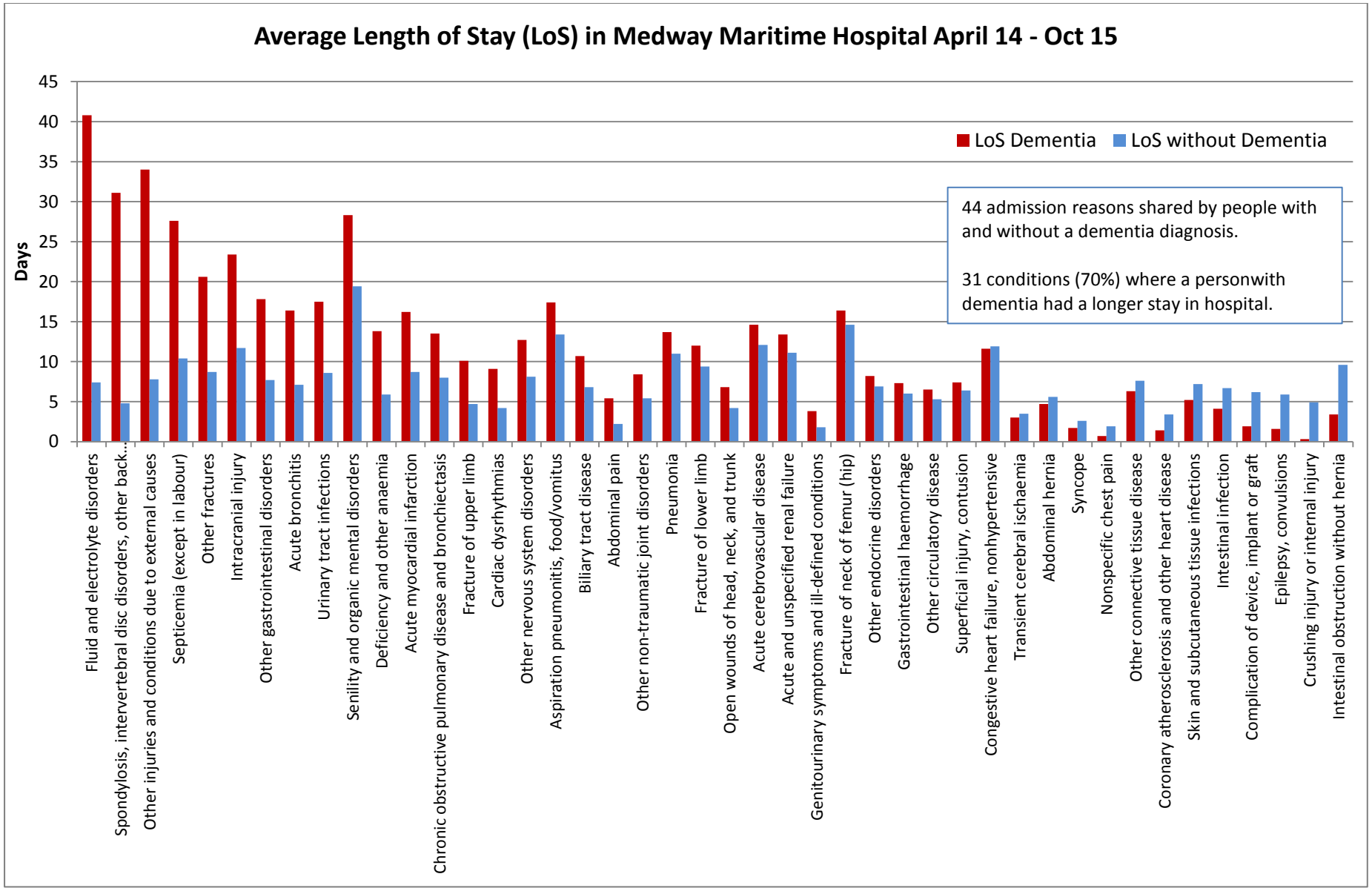

Chart 2: Average Length of Stay in Medway Maritime Hospital with Admission Reasons

Appendix 2

2. Admittance to hospital of patients with dementia for possible avoidable conditions

Although the available data (relating to patients with dementia admitted to hospital, but with another primary reason for admission) does not indicate the severity of a patient's condition, there are some conditions that could possibly be better supported in the community preventing A&E admittance. This would reduce the number of bed days and associated costs.

Medway Maritime Hospital Admission Reason	Number of Patients	Total Bed Days	Average Spell £
Chronic ulcer of skin	Data not available	137	£4,972
Conditions associated with dizziness or vertigo	Data not available	3	£1,326
Deficiency and other anaemia	14	193	£3,337
Fluid and electrolyte disorders	9	367	£7,073
Headache, including migraine	Data not available	15	£1,560
Sprains and strains	Data not available	1	£492
Viral infection	Data not available	1	£1,299
		Total: 717	

Table 1: Hospital Admittance for People with Dementia Apr 14 – Oct 15

3. Costs associated with hospital stays for people with and without dementia at Medway Maritime Hospital.

The average cost of a bed day for a person with dementia appears to be less than that for a person without dementia, for reasons which are as yet unclear[1]. Despite this, there is a significant increase in the cost of a spell in hospital for a person with dementia. This is likely to be due to people with dementia spending longer in hospital. Analysis shows that 7% of all admissions were for patients with dementia, however the same patients occupied 13% of all bed days.

The average cost of a bed day for a person with dementia is £272, or £344 for a person without dementia. Difference £72.

The average cost of a spell in hospital for a person with dementia is £3362, or £2345 for a person without dementia. Difference £1017.

[1] The question of why this should be the case is currently under investigation, via the key authorities at the hospital

Appendix 2

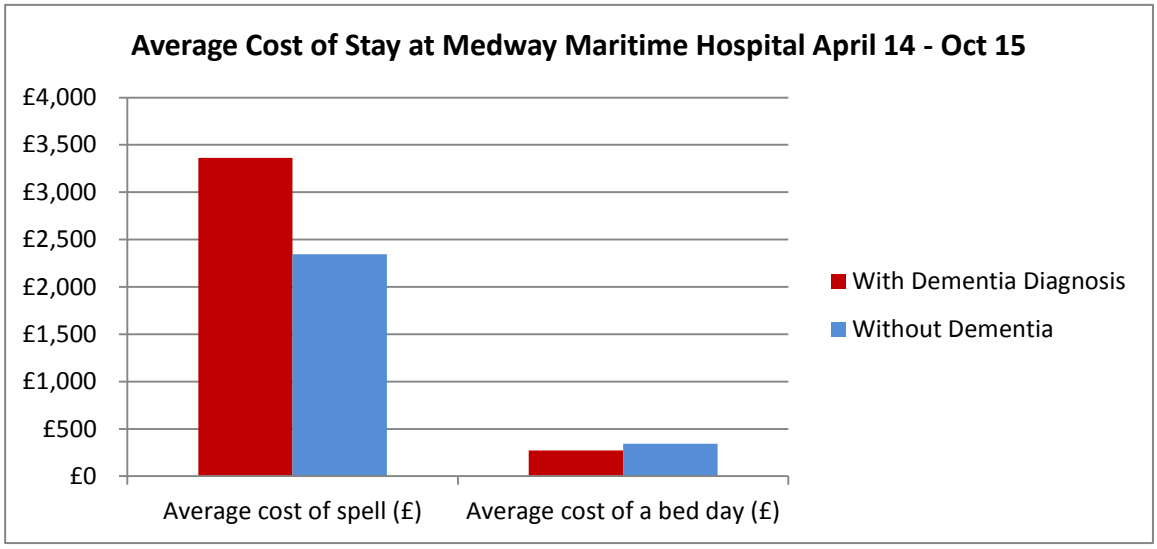

Chart 3: Average Cost of Stay at Medway Maritime Hospital

Evidence about impact of hospital admission on people with dementia

According to an article in 'The Journal of Quality Research in Dementia Issue 8' [Sheehan et al, 2009]:

'*Dementia is known to increase risk of institutionalization and mortality after hospital admission while during hospitalizations, people with dementia are at high risk of developing major complications of illness such as pressure sores, falls and incontinence.*

Furthermore people with dementia appear to be treated differently in general hospital. A UK study [Sampson et al, see below] examined the in-hospital end of life care of older patients with and without dementia who had died in hospital. Patients with dementia were less likely to be referred to palliative care, less likely to receive palliative medication, and less likely to receive specific medical interventions. This appeared unlikely to be explained by clinical differences between the groups.'

Analysis

The evidence presented in this report suggests that on average, it takes longer for a patient with dementia to be discharged from hospital compared to a patient without dementia, where the primary reason for admission is the same. This means that the average cost of a spell in hospital for a patient with dementia is greater.

The report also presents some anomalous data suggesting that the average cost of a bed day for a patient with dementia is actually less expensive, when compared to that for a person with dementia; it is not clear why this should be, and this point is undergoing further investigation.

Nonetheless, especially given evidence that the long term impact of a spell in hospital is more detrimental for a person with dementia (compared than someone without), and therefore is likely to lead to greater indirect costs to health and social care in the long run, this would suggest that there would be considerable efficiencies to be gained by ensuring more speedy, safe and person-centred discharge arrangements for patients with dementia.

However, for the purposes of this analysis, it is clear that this would not lead to cashable savings, since there would be no way of reclaiming the relevant funds from the acute trust. On the contrary, the vacant beds would be used to relieve pressures elsewhere – hence delivering improvements to Medway Foundation Trust's performance, efficiencies for the system, and benefits for patients - but not financial savings for commissioners.

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Appendix 3

Becoming a Dementia Friendly GP Practice – Experience from Hampshire (April 2015)

The iSPACE project led by Dr Nicola Decker, a GP at Oakley and Overton Surgery and dementia lead for the North Hampshire Clinical Commissioning Group, has developed a suite of resources to help make a GP surgery dementia friendly, based on her own experience as a GP.

The Dementia Friendly primary care project, iSPACE, was put into practice as a pilot initiative in April 2014 by Dr Decker at Oakley & Overton Practice, with funds awarded by the Wessex Academic Health Science Network (AHSN). The evidence underpinning this initiative was the RCN Dementia survey of 2,184 professionals, patients and carers in 2011, from which the SPACE principle was developed for use in hospital care. Dr Decker adapted this for primary care and named it iSPACE, with the purpose of improving patient and carer experience, teamwork and clinical consultations.

iSPACE Explained

iSPACE consists of 6 key steps to becoming a Dementia Friendly Practice:

1. **Identify** one or two Dementia Champions in the practice.
2. **Staff** who are skilled and have time to care.
3. **Partnership** working with carers, family and friends.
4. **Assessment** and early identification of dementia.
5. **Care plans** which are person centred.
6. **Environments** that are dementia friendly.

An evaluation by the Centre for Implementation Science, University of Southampton, found improvements to patient and carer experience, staff delivery of iSPACE and clinical consultations, with the caveat that this study was not able to control for the effects of other national schemes occurring simultaneously.

Key benefits identified:

- Patient and carer experience improved.
- Diagnosis rates increased from 52% to 63% at Oakley and Overton practice.
- Staff attitudes to dementia are more positive.
- Clinical consultations improved.

In addition, the evaluation has identified encouraging signals in the following:

- Good fit with current best practice.
- Low resource costs to implement.
- Positive potential for spread of practice across Wessex.

Dr Michele Legg of Tower House Surgery IOW said:

'This is a relatively inexpensive bundle of actions that makes a big difference to

patients and their carers in managing what can be one of the most soul destroying illnesses we encounter.'

The information contained in this briefing, and further materials, can be found via the following links:

http://dementiapartnerships.com/project/ispace-supporting-dementia-friendly-gp-surgeries-in-wessex/

http://www.actonalz.org/sites/default/files/documents/Becoming%2Ba%2Bdementia%2Bfriendly%2Bpractice%2BApril%2B2014.pdf

http://www.oakleyandovertonsurgery.co.uk/website/J82046/files/Dementia_friendly_practice_Quick_Guide_(April_2014)[1].pdf

Appendix 4

Community-Based Early Intervention Support Services for People with Dementia in Medway
Evidence Review 2016-2017

Introduction

The Alzheimer's Society currently provides a range of community based services for people with dementia in Medway. This paper sets out:

1. Current provision, including what is offered and the numbers of service users.
2. Current service costs.
3. Background to funding and support for services locally.
4. The outcomes achieved by local provision, and contribution to wider pathways.
5. Academic journals evidencing effective early intervention strategies.
6. The case for including preventative services such as those described in this report, as part of any future post-diagnostic pathways for people with dementia and their family carers.[1]

1. Current Provision

Current services in Medway provided by the Alzheimer's Society comprise: Peer Support Groups for people with dementia, Peer Support Groups for carers, Dementia Cafés in various locations across Medway, and a Dementia Support Worker service.

Peer Support Groups for People with Dementia or Carers:

These services have developed to give people with dementia and / or carers an understanding of how other people with dementia and / or carers perceive and cope with their own illness (or that of a loved one) and the problems they may encounter every day. This includes the possibility of social isolation and difficulty in accepting their diagnosis, and what this means to them and their families.

Evidence suggests that social interaction with peers is a key enabler to people living well with dementia[2]. It is recognised that health and social care professionals may have a limited understanding of what it is like to live with this unpredictable illness, for both the person with dementia and carers and families.

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1. This programme of work follows the overall direction set by the Medway Dementia Strategy (2014), and the more detailed conclusions of the subsequent Dementia Needs and Gap Analysis report, which was supported by JCMG, and subsequently by Medway Council Cabinet, in December 2015 and February 2016 respectively

2. See The National Evaluation of Peer Support Networks and Dementia Advisers in implementation of the National Dementia Strategy for England, November 2013.

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Peer support groups can be defined as facilitated groups intended to provide a forum for socialisation and learning for people with mild to moderate dementia or carers. The Alzheimer's Society finds that groups of between eight to ten participants works best, although this will need to be flexible depending on the needs of individuals within the group. The duration is usually between one and a half to two hours, and in Medway, includes a simple lunch. People may be referred to the service or can self-refer directly. Minimum staffing is two trained members of staff and / or volunteers; certainly in Medway, there is a strong role for volunteers in facilitating and supporting the peer support groups.

In Medway, groups meet once or twice per month and always on fixed dates / times. Transport is not normally provided. Sometimes external speakers attend to discuss particular topics; however, time is provided for group members to discuss their own feelings, emotions, experiences and anxieties in a safe environment.

Medway Alzheimer's Society Peer Support Groups:

Service Name	**Frequency**	**Average attendance**
Peer Support for people with dementia, Gillingham	Twice monthly	8 – 10 people (waiting list of 3 people)
Peer Support for carers, Gillingham	Monthly	6
Peer support for carers, Hoo	Monthly	8

Dementia Cafés

Peer support, as a general concept rather than a separate service, is a key component of Dementia Cafés. The three main aims of the cafes are:

- To provide information about medical and psychosocial aspects of dementia.
- To emphasise the importance of speaking openly about problems; recognition of individual problems and social acceptance are essential in this.
- To promote social inclusion for people with dementia and their families by preventing them from becoming isolated.

The cafés are not merely social get-togethers in a café style environment (though they do provide this); they also provide low level intervention of information, knowledge and support offered within an informal and understanding environment. The café is facilitated by a skilled facilitator, supported by other well-informed staff and volunteers, including those in partner organisations.

The cafés are generally aimed at people in the earlier stages of dementia, who are able to engage in and benefit from the group environment of the café. However, some people in the later stages, and especially their carers, are also able to benefit.

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There is no formal referral process or assessment to access cafés, which operate as open events. Numbers vary but a minimum of around 16 people is needed for viability. However, excessive numbers may also limit the benefits of the café, due to a risk that excessive noise may cause distress; in these circumstances, a further separate café may be required.

Cafés are generally held monthly or fortnightly and always on fixed dates. There should be a minimum of two staff members / trained volunteers and a ratio of 1:6 staff / volunteers to café participants. The service is open; no pre-booking is necessary. Transport is not provided.

Medway Alzheimer's Society Dementia Cafés:

Service Name	**Frequency**	**Average attendance**
Dementia Café Rainham	Twice monthly	36
Dementia Café Hoo	Monthly	18
Dementia Café Chatham	Monthly	14[3]

In addition, an active Alzheimer's Society volunteer has recently started a new dementia café, independently, but with the positive support of the Alzheimer's Society, at his own church in Rochester. This takes place monthly, and numbers attending so far are not recorded.

Dementia Support Workers

Support workers provide a unique service to people with a diagnosis of dementia, their carers and family and are part of a broader pathway for dementia support. Support workers take self-referrals, referrals from other Alzheimer's Society services and health and social care professionals.

Dementia support is delivered by paid dementia support workers who work with people with dementia and/or their carers. The service provides an individualised information and support service that is separate from statutory provision. In addition, dementia support workers aim to strengthen and build upon existing support networks. The service enables access to opportunities for groups of carers and people with dementia to come together for mutual support and for carers to benefit from a supportive education programme.
Specifically, dementia support workers address key outcomes relating to:

- Improving knowledge and understanding of living with dementia.

[3] The Chatham dementia café is still relatively new; it is anticipated that numbers will increase as it becomes better known locally.

- Preventing social isolation.
- Maintaining independence, choice and control.
- Accessing and building wide support networks.
- Improving coping strategies and recognising increasing difficulties.

Currently in Medway, the Alzheimer's Society provides one full time dementia support worker and two part time dementia support workers (the latter 0.75 and 0.6 FTE respectively).

2. The Current Costs of Alzheimer's Society Services in Medway

Total cost of all Alzheimer's Society services in Medway is £105,276.

i. Dementia Cafés & Peer Support Groups

	2016/2017
Staffing Costs	16,045
Local Management & Support & Essential support costs (IT, HR, finance, training, payroll)	3,454
Staff and Volunteer Expenses	2,005
Venue Hire & Catering costs	1,460
Promotional Materials	100
Facilities – phone, printing, stationery, post etc	1,515
Total	**24,579**

Costs above relate to the facilitation of the following groups as described in section 1 above. On average, 90 people per month access these services.

ii. Dementia Support Worker

Dementia Support Worker: Hours per week 2016/17	21 hours per week	28 hours per week	35 hours per week
Staffing Costs	16,632	21,393	26,154
Local Management & Support & Essential support costs (IT, HR, finance, training, payroll)	2,864	4,597	4,502
Staff and Volunteer Expenses	675	775	950
Facilities – phone, printing, stationery, post etc.	1,030	1,050	1,075
Total	**21,201**	**26,815**	**32,681**
Total annual cost	**£80, 697**		

3. The qualitative outcomes achieved by local provision

Locally, extensive anecdotal feedback has been gathered regarding the high value which people with dementia and their carers place on the range of services described above. Sample quotes included *'it's been my lifeline' – 'I don't know what I would have done if I hadn't found this café' - 'it's a safe place where I can talk to people who know how I feel'.*

Dementia Cafés: '*When we moved here from Lincolnshire we felt isolated, this really helps' - ' 'the information is great and very helpful' – 'more than once a month, once a month isn't often enough' – 'we have a chance to offload with each other, and find out what is available' – 'when you are searching for words no one interrupts you'.*

Peer support groups: '*Not worried about saying things around peers' – 'we are all going through the same' – 'tips from others really helped' – 'enables us to put the humour into it' – 'I have found that it has opened up a whole new life for me'.*

Further feedback from attendees at local dementia cafés and peer support groups indicates the added social value generated by the groups. Many people have made friends and subsequently meet up in their own time, providing continued support. One carer explained how she was in a difficult situation during an evening and was able to phone a friend that she had made at the Café.

Dementia Support Worker Service

The case study on the next page illustrates how a dementia support worker was able to support one individual couple, and prevent a potential crisis from escalating:

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CASE STUDY – DEMENTIA SUPPORT CLIENT

I have recently been supporting Mrs M who is caring for her husband. He was diagnosed with Alzheimer's disease three years ago and Mrs M had not received any financial, practical or emotional support at all. A neighbour suggested that she call the Alzheimer's Society. I had a long chat with Mrs M on the telephone and she cried a lot but mostly they were tears of relief to have someone to talk to!

I arranged to visit Mrs M at home and spent over two hours with her. She also said that she needed some respite as things were getting on top of her and she was very tired and stressed. She has to get up with her husband when he wakes at 2am because he is always fiddling with the electrical appliances and she is worried that he could hurt himself or cause a fire. Mrs M said that she has lost a lot of weight recently. She did look painfully thin. She had not been out of the house for three months.

Mrs M was concerned that she wasn't handling some situations with her husband in the best way. We talked about coping strategies.

I called Mrs M three weeks later and she was much happier. [Following my help] she had applied for, and is now receiving, Attendance Allowance. She is using that money to pay for her husband to attend a day centre once a week to give her a break. Her husband is really enjoying the day centre and has made some new friends there. She has been trying out the suggestions for dealing with her husband's behaviour and things have calmed down a lot at home. I will follow up with Mrs M soon and in the meantime she will ask her neighbour to take them to our Dementia Café so that they can meet people in the same situation.

4. Evidence of Effective Early Intervention

International and national research evidences effective early intervention strategies as part of care pathways to improve outcomes for people with dementia and carers.

Peer Support Groups:

One study looked at dementia peer support groups to understand the wider value and positive outcomes delivered by these groups[4].

Positive outcomes for people with dementia included:

- A reduction in loneliness and isolation.
- A feeling of stimulation, more than if they remained at home.
- An increase in wellbeing from having a sense of purpose and enjoyment.
- A feeling that their identity and personhood is promoted, improving wellbeing.
- Feeling part of a welcoming community, creating a feeling of trust and belonging.
- Feeling fitter as a result of taking part in regular exercise activities.

[4] Peer Support for People with Dementia: A Social Return on Investment (SROI) Study. Health Innovation Network, Sep 2015

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Positive outcomes for carers included:

- A reduction in stress and burden of care.
- An increased sense of wellbeing from being involved in the group.
- A reduction in feelings of loneliness and isolation.

Positive outcomes for volunteers included:

- An increased sense of well being.
- An increased level of knowledge that benefits themselves and others.
- More transferable skills.
- Feeling part of the community.

Three peer support groups were used for the study. Based on detailed methodology described in the report, all three groups produced a positive SROI ratio, indicating that the social value created is greater than the cost of investment. The strength of the ratio varied between groups due to the difference in group structure and outcomes produced.

Personalised approach

An American study looked at strategies aimed at delaying admission to institutionalised care for patients with dementia (*Spijker et al., 2008*). The study found that a combination of involvement and choice was the main intervention characteristic distinguishing effective support programs from ineffective ones. Effective support programs included counselling and personal assistance with problem solving, and offering carers a choice of support strategies and services.

A Danish intervention study, focused on the benefits of a range of early intervention support, including peer support groups, also concluded that programmes which involve patients and their carers in an intensive and personalised way were likely to be more successful (*Lisbeth et al., 2008*). Patients and carers found the programme stimulating and rewarding; they felt they could cope better and didn't feel alone.

Physical exercise programmes

Physical exercise programmes have been shown to be effective in delaying the impact of symptoms for older people with mild to moderate dementia (*Medical Advisory Secretariat, 2008*). National Institute for Health and Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE) advise that physical exercise programmes should be part of the care pathway for people with dementia in order to promote and maintain independence (*NICE_SCIE, 2011*).

Appendix 4
Support for Carers

A psychosocial intervention for family carers was studied in Sweden. It found that counselling sessions and conversation groups resulted in significant delays in nursing home placements for the people with dementia they were supporting, compared to standard care and support programmes (*Andren S et al., 2008*).

A meta-analysis of psychosocial interventions for carers of people with dementia found that interventions do have significant positive outcomes for carers and the person they care for (*Brodaty H et al. 2003*). It found that interventions reduce carers' psychological morbidity and help people with dementia stay at home longer. Programmes that are personalised to individual carers needs and are more intensive may be more successful. The study also found that brief interventions or courses that were not supplemented with long term contact are not effective.

Economic benefits

A Monte Carlo cost benefit analysis suggested that early diagnosis and treatment of Alzheimer's disease has the potential to result in large positive social and economic benefits (*Weimer et al., 2009*). The findings also suggest that a failure to fund effective informal carer interventions may be economically unsound. It stated that carers play a key role in successful dementia management programmes and should not be ignored.

5. The key role of early intervention services in Medway

Detailed research and discussions with partners across the health and social care system, as well as with people with dementia and carers, conducted to inform the Dementia Commissioning Needs and Gap Analysis (December 2015), have illustrated that the preventative support services provided by the Alzheimer's Society (as well as those provided by other voluntary organisations such as Age UK and Carers First) form an essential part of the care pathway for people who have been recently diagnosed and in the early to middle stages of dementia in particular.

For most of these individuals, indeed, there is very little other dedicated ongoing support available. Several people with dementia and carers – especially those who did not immediately find their way to the Alzheimer's Society services following their diagnosis - said that after being diagnosed, it was '*like being pushed off a cliff into a black hole'*, and other similar comments.

An integrated approach would recognise and strengthen the key role which early intervention and prevention plays in delivering effective care pathways for people with dementia, in helping to prevent crises and carer breakdowns, and reducing inappropriate or preventable admissions of people with dementia to hospital.

Appendix 4

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