Review of the Dementia Framework West Sussex 2014-19

EXECUTIVE SUMMARY

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1.0 INTRODUCTION & METHODOLOGY

Launched in 2014, our five year strategy for Dementia, the Dementia Framework West Sussex set out joint priorities for commissioning care and support for people affected by dementia. It was based on the views of a whole range of different people and organisations and was informed by national and local guidance, policies and data. The Framework was scrutinised by a Health & Social Care Committee (HASC) Task and Finish Group and signed off by the Joint Executive of the Crawley and the Horsham and Mid Sussex CCGs, the Coastal West Sussex CCG Clinical Commissioning Executive and the Joint Commissioning Steering Group.

A Joint Implementation Group (JIG) worked together to energise and influence commissioning and provision and to share information on plans being taken forward in the various provider areas across county. Apart from the JIG which disbanded relatively early in the Framework, there was no requirement for any ongoing governance.

As the Dementia Framework covered the period to 2019, approval was given by the HASC Business Planning Group to conduct a full review of the progress made and identify where the gaps remain.

The review was led by the County Council and all three Clinical Commissioning Groups and overseen by a task and finish group comprising representatives from health and social care and voluntary and community sector organisations. Recommendations were based on contract performance data and on findings from an extensive stakeholder engagement exercise that took place during summer 2018. The engagement consisted of two on-line surveys, and focus groups and interviews with a whole range of different people and organisations. Approximately 400 people from across the county took part in the engagement. A summary of the findings from the engagement can be found in Appendices A to E.

2.0 KEY SUCCESSES

The dementia prevalence rate has continued to rise in line with the ageing population since the start of the Framework in 2014 and prevalence is expected to grow year on year. This, together with national and local policies, guidance and legislation has helped shape the way dementia care is delivered locally and impacted on the outcomes of the Dementia Framework.

2.1 Prevention, health and wellbeing

'Prevention' outcomes within the Framework were aligned around Public Health's plans but also included outcomes around Communications and Annual Health Checks for people with learning disabilities.

- Public Health have run regular campaigns since the start of the Framework to promote smoking cessation, physical activity, alcohol reduction and NHS Health Checks with a degree of success. The NHS Health Check has sought to educate people about the risks of dementia and there are ongoing campaigns and work with Public Health to further promote the Check**.**
- The West Sussex Wellbeing programme and Hubs have helped to promote health and wellbeing for all including people with dementia. Since the start of the Framework, they have supported around 9,000 adults a year to improve their health and wellbeing.
- Information about the health risks around dementia have been communicated to residents through the Council's website, articles in town and Parish newsletters, West Sussex Connections and radio interviews.

2.2 Dementia diagnosis

- The Clinical Commissioning Groups (CCGs) have committed considerable time to improving local diagnosing rates and have training and processes in place to support the identification of the early signs of dementia. The national target set for diagnosing dementia has stood at 66.7%, and in the four years since the start of the Framework the diagnosis rate in West Sussex increased from 46% in 2014 to 58% in 2017. As of October 2018, the diagnosis rate for Crawley was 68.4%, Horsham & Mid Sussex 71.39% and Coastal West Sussex 66.14%. The number of people registered with GP's has risen in line with this.
- Sussex Partnership NHS Foundation Trust in partnership with Alzheimer's Society is commissioned to deliver a Memory Assessment Service (MAS) which provides a diagnosis and time limited treatments for all groups of people and family carers.

  Referrals into the service have increased exponentially since the start of the Framework and although 60 to 70% of all people receiving a diagnosis have a memory related condition (dementia + mild cognitive impairment), an average of only 39% of all people referred have a final dementia-related diagnosis.
- In the last four years, there has been a 7% increase in the number of people receiving a diagnosis of dementia from MAS and a rise of 90% of family carers accessing support from a Dementia Adviser which can be attributable to the renewed focus on family carers.
- The service has seen a slight increase in referrals from non-white British people but there continues to be an under-representation from these communities.
- The level of referrals into the MAS from people with learning disabilities has been consistently low with an average of just 4 people being referred to the MAS annually from the Learning Disabilities Community Mental Health team.

2.3 Post-diagnostic support

- Once people have had a diagnosis of dementia, Dementia Advisers and Dementia Support Workers, jointly commissioned through Alzheimer's Society, offer information, advice and support to the person and their family carers. The Dementia Support Service covers the whole of West Sussex and sees around 100 people with dementia and family carers each month.
- The Living Well With Dementia (LWWD) and Dementia Crisis Services (DCS) support people with complex and behavioural issues. The DCS provides more intensive interventions and has a particular remit to prevent immediate unscheduled admissions to hospital, inpatient care or nursing or residential care. The DCS has helped avoid an average of 4,000 admissions in total in the last four years.
- Proactive Care Teams provide ongoing support to people with long term conditions including dementia. They are multi-disciplinary teams where health and social care staff work together to coordinate care in order to shift the balance away from reactive crisis intervention and unplanned care/hospital towards independent health and wellbeing.
- Communities of Practice (COPs) in the north of the county provide a new way of working by integrating Proactive Care and District Nursing teams. Local Community Networks (LCNs) in Coastal West Sussex aim to deliver joined up care within local communities. Bringing together multi-disciplinary staff who work as one team with people and carers to provide holistic care and support.

  The proactive approach, integrated coordination and service delivery organised by the above services is undoubtedly making a significant positive difference to patients and family carers.

2.4 Dementia friendly communities

- There is now a Local Dementia Action Alliance (LDAA) in almost every major town in West Sussex. Each LDAA has worked hard to make its community a welcoming, accessible place for people living with dementia and there have been some good examples of this work. See Appendix G for more information.

  Many public sector organisations such as; the County Council, CCGs, Local District and Borough Councils and LCNs, actively support the work of the LDAAs but unfortunately there is no universal approach and this support varies from district to district.
- The County Council has made a public ongoing commitment to becoming a dementia friendly organisation and carer friendly employer. 250 members of staff to date have become dementia friends and a carers staff policy and 'passport' has been introduced.
- The Police and Fire and Rescue services have gone a long way to ensuring their Officers are suitably equipped to help people with dementia and many have become Dementia Friends and Champions. In 2018, the Police Service launched the Herbert Protocol. This is a tool for assisting a search if someone should go missing.
- The library service has been instrumental in providing welcoming and supportive places for people with dementia. It hosts dementia drop-in sessions in partnership with Alzheimer's Society; holds reminiscence collections; operates memory management library cards and runs Reading Well Books on Prescription for Dementia.

2.5 Family and friend Carers

- Carers Support West Sussex is the preferred provider for statutory Carer Assessments, these assessments can help identify a carer's needs and provide access to direct payments for eligible customers.
- Carers Support West Sussex is also jointly commissioned to support all family carers across the whole of West Sussex as a universal Carer 'Front Door' for carers who have not necessarily come into contact with other services.

  Carers Support West Sussex provides support via the generic Carer Response Line, a small specialist dementia support team and carer groups, information, signposting and; free counselling; free therapy taster sessions; a Carer Equipment Service; Carer Learning and Wellbeing programme; and light-touch Carer Wellbeing Reviews. Carers have access to a Carer Health and Wellbeing Fund which is a non-means tested pot of funding that can provide a one-off payment to meet an assessed need in the carer's life.

  An estimated 4,782 carers of people with dementia are being supported through Carers Support West Sussex.
- Alzheimer's Society's Dementia Advisers and Dementia Support Workers are commissioned to provide information and support to people with dementia and their carers at the point of diagnosis and later in a person's journey. Alzheimer's Society also deliver training for carers through their Carer Information and Support Programmes (CrISP).
- Short breaks and respite opportunities (some dementia specific) designed to give carers a break from their caring role are jointly commissioned through a range of voluntary and community sector organisations. These services can either be in the person's own home or through group activities, day services and dementia cafes. They are delivered county-wide through a variety of providers.

- Sussex Community NHS Foundation Trust's (SCFT) Carer Health Team is a clinical team jointly commissioned to work proactively with the carer to ensure they are considering their own health and wellbeing. Although not dementia specific, in the last quarter of 2016/17 there were approximately 300 referrals into the service of which 30% were from people caring for someone with dementia.
- In 2015, an Admiral Nurse service was commissioned in the north of the county by Horsham & Mid Sussex and Crawley CCGs to support family carers of people with dementia. It works with around 24 referrals a month and a 2017 evaluation of the service pilot reported 90% of family carers have reported receiving better support in their caring role.
- Dementia mainly affects older people but for some, dementia can develop at a younger age. There is estimated to be over 200 people under the age of 65 predicted to have dementia in West Sussex. Three discrete groups running in different areas of the county are jointly commissioned to meet the needs of younger people with dementia.

  In response to an identified need, a service aimed at providing a meaningful overnight short break for family carers of younger people was launched in 2017. The break is designed to provide age appropriate activities in a mainstream setting. A total of 60 people to date have been reached through this service.
- The Council commissions a thirteen week free telecare service and a universal offer of assistive technologies that enables people with dementia to live independently at home for longer. There are around 400 telecare installations taking place each month, of which an average of 15% are for people with dementia. These customers are sign-posted to additional support. Dementia has also been identified as a priority area in the newly launched Technology Enabled Lives Strategy (TELS).
- A pilot to test a Shared Lives Service for people with dementia was commissioned early in the Framework. Some success was identified with recruiting host carers but there were few successful placements. The pilot has now ended but Shared Lives placements can still be offered to people with dementia if a suitable host carer is available.

2.6 Hospital care

- A 2017 National Audit of Dementia Care in General Hospitals[1] reported improvements in the care provided by all acute hospitals in West Sussex. All scored 80% on nutrition and hydration; two thirds of carers felt the care their loved one received was good; and almost all staff reported the training they had received made them better prepared to care for someone with dementia.
- The following are some good examples of dementia care taking place in our acute and community hospitals:
  - The 'Butterfly scheme' at East Surrey Hospital is designed to help all staff to better support people with dementia or memory difficulties. The hospital also has dementia leads in every ward and a dedicated Admiral Nurse supporting carers to cope with their caring role. The Admiral Nurse also facilitates music projects, dementia cafes etc.
  - In 2016, SCFT launched a 'Connect with Dementia' service supported by volunteers at Crawley Hospital and Zachary Merton. This service is ongoing and seeks to support people with dementia whilst in hospital.

[1](Audit commissioned by the Healthcare Quality Improvement Partnership (HQIP). report is produced and published by the Royal College of Psychiatrists' Centre for Quality Improvement.)

- Acute hospitals mostly now have open visiting hours. This offers family and friend carers more flexibility plus the reassurance of being able to be alongside the person they normally care for at a critical time.
- Carers Support West Sussex Carer Wellbeing Workers work with integrated hospital teams in all acute hospitals seven days a week and are available to support carers in all the community hospitals too. They provide a direct single point of access, contributing to reduction in admission, length of stay and re-admission and better outcomes for patients and carers.
- Information tools such as 'This is About Me' and 'Knowing Me' are being used in all the hospitals to enable ward staff to provide care individual to the needs of the patient.
- SCFT's Dementia Community Matrons support people with dementia and memory loss in Adur, Arun and Worthing either in their own homes or a residential care setting. They work to avoid admissions and support early discharge from hospital.
- The Relative Support and Home from Hospital services work across all West Sussex hospitals to offer support to carers, whether it is they or the person they are caring for who is the patient.
- Three dementia acute wards in Horsham, Chichester and Worthing provide intensive multi-disciplinary treatment and interventions for people of any age who are diagnosed with dementia and experiencing severe behavioural and psychological distress. A review and reconfiguration of this service is currently taking place with the aim of achieving a centre of excellence.
- Dementia is a national priority for the Ambulance Service and the South East Coast Ambulance Service (Secamb) now has a dementia lead in place and a wish to see paramedics receiving mandatory dementia awareness training.

- The county-wide Dementia Crisis Service supports the person at risk of an unplanned admission to keep them out of hospital.
- The CCG's and County Council are actively working to reduce the time people spend in hospital by increasing quality and supply within the care market and reducing the time people wait for assessment of their needs and funding decisions.

2.7 Care Provider Market

- There are currently around 72 care agencies in West Sussex registered by the Care Quality Commission (CQC) as accepting referrals from people with dementia, 64% are rated 'Good' with 9 agencies being rated as 'Outstanding'. 33% of all agencies are based in Horsham and Mid Sussex, 59% in Coastal West Sussex of which 20% are in Chichester and Bognor area and just 8% in Crawley.
- There are around 128 nursing and residential care homes registered in West Sussex that support people with dementia. Around 92 have been rated 'Good' or 'Outstanding' by the Care Quality Commission (CQC). Of the 128 homes, 66% are based in Coastal West Sussex of which 27% are in the Chichester and Bognor area, 30% in Horsham and Mid Sussex and just 5% in Crawley.
- The County Council commissions two care provider frameworks which are used by health and social care professionals for spot purchasing placements and packages of care. Providers on the framework work towards quality standards which include ensuring staff receive the necessary training in dementia and person-centred care.
- The Council and NHS support the care sector to improve quality and supply and workforce retention and recruitment.

2.8 Training and education

- There are a variety of training programmes in dementia care being rolled out to the Local Community Networks, Communities of Practice, care providers, Secamb and hospitals. And the new Care Certificate, mandatory for all care staff, includes modules in person-centred care and dementia awareness.
- Launched in 2017, the West Sussex Dementia Care Learning and Development Framework provides a single point of access to training and information for all people and organisations supporting someone with dementia. It was designed in partnership with a whole range of people and organisations including family carers.
- An innovative training programme, Time for Dementia, has been particularly well received by many of the people consulted as part of this review. This programme provides undergraduate healthcare professionals with ongoing, regular contact with people affected by dementia as part of their curriculum.
- Coastal West Sussex CCG directly commissions End of Life Education with the local hospices and specialist palliative care providers that is open to partners and includes end of life care for people with dementia.

2.9 End of Life Care & Advance Care Planning

- Work is being undertaken across West Sussex to encourage and support individuals to plan for their end of life care and there is a whole systems commitment to an Advance Care Plan entitled 'Planning Future Care' that is in the process of being implemented across West Sussex.
- Secamb has the practice of holding Advance Directives on their systems to inform them of a person's wishes about their healthcare if they are no longer able to make decisions for themselves. There are issues around ensuring the service has the most up-to-date version of the Directive and sharing it with other services.
- The End of Life Care Hub for Coastal West Sussex (ECHO) helps to improve identification of people in the last year of their life and provides a more responsive proactive approach. It provides a register of people accessible to clinicians, a website and a 24 hour telephone line. It reacts to patients' changing needs by co-ordinating access to services. An evaluation of the service is currently being completed but eighteen months into the service, early indications are that ECHO is working well.

3.0 WHAT STILL NEEDS TO BE ACHIEVED

3.1 There are a few good examples of **services working together** but issues around referral pathways and sharing information between services. Communities of Practice in the north of the County represent a true integrated approach to care and support with co-location of health and social care staff. It will be important to explore how this approach can work with other areas of the county so that people can benefit from joined up care and support that is individual to their needs.

3.2 People wait a **long time for diagnosis** from MAS, often more than 4 weeks from referral to first assessment. Long waits can make people anxious and often people referred into the service drop off the waiting list or go into crisis.

The MAS is currently testing a new diagnostic pathway in Worthing that looks to reduce waiting times and early results are proving promising. If the pilot is successful it will be rolled out to the rest of the county during 2019. The new model will need to be monitored carefully to ensure waiting times reduce sufficiently and at pace.

Consideration also needs to be given to how people access **support whilst they await their diagnosis**. There will need to be robust referral mechanisms put in

place to services such as Carers Support West Sussex. However the small Carers Support West Sussex dementia team is over-stretched and at full capacity.

Ongoing investment in the diagnostic pathway will be necessary to ensure people do not experience long waits to diagnosis and have access to support while they wait.

3.3 For people from **diverse backgrounds** such as BAME, Gypsy and Travellers and LGBT communities and people with **Alcohol Related Dementia**, more needs to be done to ensure there is a clear and robust pathway to diagnosis and support that is person-centred and sensitive to the needs of all groups of people. Services designed to provide care and support for people with dementia need to be inclusive and understanding of different needs.

3.4 For **people with learning disabilities,** improvements need to be made with the diagnostic and post-diagnostic pathway to ensure people receive an early diagnosis and ongoing support from care providers skilled in caring for both dementia and learning disabilities. Annual Health Checks make it easier for a diagnosis of dementia to be made at an early stage. However, the number of people receiving this health check is low with around only 26% of people with learning disabilities on GP registers taking up the offer. This represents only half the number of people eligible to take part. More needs to be done to ensure the signs of dementia are spotted as early as possible so that the person with learning disabilities can receive an early diagnosis.

3.5 For **people with sensory loss**, the MAS is equipped to provide a good quality diagnosis but people also need to be able to receive accessible information and communications and they and their family carers should be able to participate in meaningful activities that are appropriate to them. There are currently no groups or activities designed to meet the needs of people with dementia and sensory loss.

3.6 There have been issues with the uncoordinated way **information and advice** is provided. People affected by memory loss and others may rightly seek information and advice from any number of touch points across the county throughout their journey. There is however no co-ordinated approach to how information and advice is accessed or any joined-up communications to achieve system-wide consistency of easy-access information and commonality of language used.

It will be important to look at different examples of best practice when developing any future refresh of the Dementia Framework, for example, Sage House at Tangmere. This service seeks to bring services under one roof with easy access to information and advice through its innovative Wayfinding service.

3.7 **Care planning including end of life care -** People affected by dementia told us that there was a lack of clarity about what they could expect in the future and how they could access support when their needs changed. Care Plans and Advance Care Plans need to be produced as early as possible in the person's journey.

The plans should not just be medical but take a holistic approach and should be developed in conjunction with the person and their family carer. The plans need to be re-visited on a regular basis to ensure they are up-to-date and, where consent is given, shared with all professionals involved in the person's care. A named co-ordinator should be identified who will keep the person and their family at the centre of any decisions that affect them but this is not currently taking place.

3.8 Health and social care workers have told us of the challenges they face with **supporting people with complex and challenging behaviour**. There is

support available from Dementia Matrons, Admiral Nurses, the Living Well and the Dementia Crisis Service but these services are at capacity and struggle to meet the increasing demand. It will be necessary to continue to ensure there is sufficient investment in services that help prevent unnecessary admissions to hospital and long term care.

3.9 The **demand for care** continues to grow but there is lack of capacity within the local care market particularly for people with complex and challenging behaviour. Investment in the work taking place to facilitate the local care provider market needs to continue in order to meet the increasing demand.

3.10 People affected by dementia need to be able to **participate in their communities and pursue meaningful activities** that help them to live well with the condition. Access to the right level of support for the person as their dementia progresses can help them stay in their own homes for longer. Day services, clubs and groups are commissioned to provide a meaningful break for older people including people living with dementia. These run throughout the county through a range of different organisations. However, carers say that there are few services that will provide care for the person once their dementia progresses, for example; personal care.

3.11 **Family and friend carers** need to have access to the right kind of local support that is appropriate to them to enable them to continue in their caring role. However, 25% of respondents to the on-line survey reported not having had a break from their caring role. This is critical to keep people with dementia living in their own home for longer thus reducing the impact on capacity within the care market and other services. The review also identified family carers feeling they were not always being identified as 'partners' in their loved ones care by agencies providing care and support for their loved one.

3.12 Supportive **dementia friendly communities** are key to ensuring people affected by dementia can fully access their local area and any support and activities available to them but only 20% of respondents to our on-line survey felt their community was dementia friendly. This could be an indication of the amount of work still left to do and investment in this area will be key. This will call for some robust joint working between the Local Authority, CCG's, Local District, Borough and Parish Councils and community and voluntary sector providers to help identify solutions, resources and funding. A whole community approach providing cross-generational awareness is required. Properly commissioned Dementia Alliances and local Dementia Wellbeing Programmes could be the core elements of a future framework.

Public sector organisations are well placed to lead by example by establishing dementia friendly and carer friendly staff policies and guidance for their employees, supporting the roll-out of dementia friends training in their workplaces and ensuring their public facing buildings are dementia friendly environments.

4.0 CONCLUSION & RECOMMENDATIONS

There has been some good progress made since the launch of the Dementia Framework in 2014 but there is still more to do. The rise in the prevalence of dementia together with complexity has impacted greatly on capacity within services and it will be important to ensure future investment can continue to meet the rise in demand. 'Ring-fenced funding' for post diagnostic support and co-ordinated systems between health and social care to support joint commissioning will be crucial to support the needs of this population.

It is recommended that the 2014-19 Dementia Framework is refreshed to reflect findings from this review and recent national and local policies, guidance and legislation. New priorities for 2020 to 2025 should be set and a joint delivery plan developed and agreed with a plan for coordinated local implementation.

There was a lack of governance around delivery of the 2014-19 Dementia Framework which made it difficult to deliver on the outcomes effectively. Robust monitoring, governance and leadership will therefore be necessary for the refreshed Framework and it is recommended that a Delivery Board oversees the work to ensure there is sustained progress. The Delivery Board will need to have a status to be in a position to influence commissioning in context of increasing demand elsewhere across the health and social care economy. The Board will need access to social value and health economics information to build a business case for any future investment opportunities.