

Health and Adult Social Care Scrutiny Committee
11 March 2020
West Sussex Joint Dementia Strategy 2020-23
Report by Executive Director, Adults and Health

Summary

It is anticipated that in 2020 the prevalence of dementia will have reached over 16,000 people and this is expected to grow by 35% in the next 10 years with many people living with more than one long-term health condition. To be able to continue to offer a timely diagnosis and post-diagnostic support, there needs to be a focus on: how people can reduce the modifiable risks of dementia; how we can better support carers in their caring role; supporting people at risk of a crisis and how we go about targeting resources designed to keep people independent for longer and away from more expensive residential and nursing care.

The West Sussex Joint Dementia Strategy 2020-23 is the county's second dementia strategy. It builds on the progress made over the last five years in improving the experience of people with dementia, their families and carers. Setting out the Council's commitments, the Strategy provides a framework for further action to ensure the realisation of the Council's shared vision for dementia in West Sussex.

The Strategy aligns with the key priorities of the NHS Long-term Plan and West Sussex Plan around independence for later life.

Focus for scrutiny

The Health and Adult Social Care Scrutiny Committee is asked to consider the priorities set within the West Sussex Joint Dementia Strategy 2020-23 around the dementia well pathway particularly, the diagnosis and post-diagnostic stages, taking into consideration the key areas of focus for scrutiny, as outlined in section 9 of the report.

The Chairman will summarise the output of the debate for consideration by the Committee.

1. Background and Context

- 1.1 Dementia affects around 850,000 people in the UK and in West Sussex it is anticipated that in 2020 there will be 16,650 people living with late onset dementia which includes 500 younger people. These figures are set to rise by 35% in the next 10 years.
- 1.2 People with mild symptoms will normally be able to remain independent in their own home but for some people in the 'Moderate' and those in the

'Severe' categories, more support and perhaps long-term care may likely be needed.

Severity	2020	2025	2030
Mild	9,200	10,750	12,450
Moderate	5,350	6,200	7,200
Severe	2,100	2,400	2,800

- 1.3 There is a considerable economic cost associated with dementia with many people also living with one or more other health conditions. The County Council currently supports around 850 people over the age of 65 requiring support with their memory and cognition at an average total weekly net cost of £290,000. Much of this cost (85%) is accountable for by long-term residential and nursing care. Dementia services commissioned by the Clinical Commissioning Group cost in excess of £10m annually and the cost of emergency inpatient admissions for people with dementia is estimated to be £1.6m.

It should be noted that 68% of costs associated with dementia are for unpaid care such as the care provided by family and friend carers.

- 1.4 Dementia is a key priority for both NHS England and the Government. In February 2015 the Prime Minister launched his Challenge on Dementia 2020, which set out to build on the achievements of the Prime Minister's Challenge on Dementia 2012-2015.

The NHS Five Year Forward View set out a clear rationale for providing a consistent standard of support for people with dementia and their family and friend carers. Ageing well and caring for people with dementia are both key priorities in the NHS Long-term Plan and the West Sussex Plan sets out priorities around independence for later life.

- 1.5 In 2014, West Sussex County Council in partnership with all three Clinical Commissioning Groups (CCGs), launched its first joint strategy for dementia; the Dementia Framework West Sussex 2014-19.

- 1.6 A full review of the Dementia Framework took place in 2018 and findings have been used to refresh the strategy's priorities. The review was based on health and social care performance data and on findings from an extensive stakeholder engagement exercise.

- 1.7 The review found that there had been some progress since the launch of the Dementia Framework in 2014 with, for example, an increase in the diagnosis rate which rose from 46% in 2014 to 74.3% in 2020; an improved offer of post-diagnostic support for the individual and their family carers from Dementia Advisers and Dementia Support Workers; and the growth of dementia friendly communities, there are now 10 Local Dementia Action Alliances in the county with around 300 members committed to becoming dementia friendly businesses and organisations. There were however areas identified where little or no progress had been made and these gaps have been highlighted as priority areas within the refreshed

strategy.

- 1.8 The West Sussex Joint Dementia Strategy 2020-23 is West Sussex's second dementia strategy. It builds on the progress made over the last five years in improving the experience of people with dementia, their families and carers. Setting out our commitments, the strategy provides a framework for further action to ensure the realisation of our shared vision for dementia in West Sussex.
- 1.9 A task & finish group comprising representatives from health and social care statutory and voluntary and community sector providers have helped to drive through the development of the strategy. Alongside this, five focus groups comprising people living with dementia and/or family and friend carers from Worthing, Crawley, Horsham, East Grinstead and Chichester have helped inform and advise on the priorities.
- 1.10 The task & finish group identified a number of key 'gaps' in the pathway and there have been multi-agency sub-groups exploring the gaps in more detail. The sub-groups have focused on: support for people with complex and challenging behaviour; sustainable Dementia Friendly Communities; establishing a pathway to diagnosis and support for people from minority groups, people with learning disabilities and people with alcohol dependency; enabling people living with dementia and carers to access information and advice and meaningful activities and care and contingency planning.

2. Proposal

- 2.1 The Strategy is set around the Dementia Well Pathway which has five elements based on the themes outlined in the Prime Minister's Challenge on Dementia. They reflect the breadth of the experience of people with dementia, their families and carers from 'Preventing Well' through to 'Dying Well'. It is essential that family and friend carers are represented across the whole pathway and regard has been given to the priorities of the Joint Commitment to Carers strategy when setting our goals.
- 2.2 In West Sussex, there is a wide range of care and support available for people with dementia and their families and carers but this is often patchy and people often get lost trying to navigate the 'system'. We know people living with dementia face a variety of challenges and have a range of needs so to achieve our vision it is key that organisations work collaboratively. The Dementia Strategy represents the combined views of many partners, each of whom is committed to working together to make life better for people affected by dementia.
- 2.3 The following sections give an overview of the priorities set for each stage of the pathway and the areas of focus. A delivery plan will provide more detailed actions and measures for our ambitions in years 1,2 and 3.

3. Preventing Well

- 3.1 This is the first stage in the pathway and goals have been set around; reducing the modifiable risks of dementia including the need for social interaction, how we reach people at greater risk of dementia and early intervention for hearing and sight loss. Areas of focus for the strategy are those services aimed at promoting health and wellbeing and social interaction such as the social prescribing service; the Wellbeing Hubs and uptake of the NHS Health Check which can spot the early signs of dementia and provide information about the risks.
- 3.2 Given the evidence of a link between hearing loss, cognitive decline and dementia, early intervention and on-going support for any underlying hearing loss may have an important role to play in reducing both the risk and impact of dementia.

4. Diagnosing Well

- 4.1 This stage focuses on timely diagnosis and care planning and raising awareness of the early signs of dementia and the benefits of diagnosis. Areas of focus for the strategy are the diagnosis rate, the time people wait for their diagnosis, how people access information and advice and support with care planning.
- The Memory Assessment Service (MAS) continues to provide a good quality diagnosis and post-diagnostic interventions for the patient and their carer, but the ever-increasing rise in prevalence has put a strain on capacity. There will need to be continued investment into the MAS in order for it to keep up with the rising demand.
 - In 2018/19, the MAS made 1,525 diagnoses of dementia, but only 3% were from people from Black, Asian and minority ethnic (BAME) groups. There needs to be an emphasis on how we reach people from hard to reach groups with information about; prevention, identification of the early signs and the positive benefits of receiving a diagnosis. A sub-group is currently exploring how we take this forward.
 - For people with learning disabilities, younger people and people with alcohol related dementia, there are particular challenges around timely diagnosis because symptoms are not always picked up early enough. A sub-group has been set up to establish a more robust pathway to diagnosis and post-diagnostic support for these groups of people.
 - The wait to diagnosis can often be long, this has led to people 'dropping off' the waiting list perhaps because of anxiety. We have rolled out a new Dementia Assessment Service in the south which is a one stop shop for patients which has reduced the dropout rate from 40% to 20% and worked with hospitals reducing scan times from 32 weeks to 5-8 weeks.
 - This Strategy highlights the need for the individual and family carers to have a seamless route to information, advice and support during the waiting period and post-diagnosis. There will be a focus on ensuring there is a robust referral route from the MAS to providers that are able to support the person and/or their families and carers across the pathway.

- Care plans are the lynchpin of good post diagnostic support and simply having a care plan, whilst being a good start, is not enough. Any care plan needs to be personalised to the specific needs of each person with dementia and reflect changes in their care needs over time. A sub-group is looking at designing a holistic care plan that can be used by the individual, their families and carers and all those involved in the person's care throughout their journey.

5. Supporting Well

5.1 For many people dementia is not the only long-term condition they live with and they need to be enabled to manage the dementia and other conditions as much as possible for themselves, a collaborative approach across providers is key to enabling this. Areas of focus for the strategy are around enabling people to live independently for longer, a workforce skilled in dementia care, crisis prevention and the avoidance of unnecessary hospital admissions, long stays and delays to discharge.

- People need to be enabled to live at home as long as possible and housing needs to meet their changing needs. Local house planning therefore needs to reflect the growing need and the rise in prevalence across the county. Housing providers can also play a key role by supporting Dementia Friendly Communities and ensuring their staff are dementia aware. They can help identify the symptoms of dementia and encourage them to seek support.
- There also needs to be a clear offer of equipment and assistive technology that optimises the individual's wellbeing and independence and support for the carer.
- People with greater needs, may require more support and it is important there is a workforce across the dementia care system that has the right skills, behaviours and values to provide compassionate, culturally sensitive, person-centred care. It is therefore important all providers have a framework for dementia training in place that ensures staff receive training relevant to their role.
- Contributory factors to a crisis such as carer breakdown, physical health problems or social factors related to the person with dementia or their environment need to be identified by health and social care providers early on and interventions provided where necessary. Contingency planning with the individual and their families and carers should take place early as possible in the person's journey.
- People with dementia are at greater risk of an unnecessary hospital admission usually because of falls, urinary track infections (UTI's) etc. Stays in hospital are often longer and there can be delays in discharge often because of the time taken to arrange packages of care. Health, social care and community and voluntary sector providers need to work together to provide a joined-up approach to supporting the person at risk of an unplanned hospital admission or delayed discharge and tools such as 'Knowing Me' that provide key information for hospital staff about their patients need to be utilized.

6. Living Well

6.1 There is potential for people with dementia to live meaningful and satisfying lives, but this requires support from all those people and services surrounding the person including their own community. Areas of focus for the strategy are around; the need for safe, accessible and welcoming communities, supporting family and friend carers, and access to information and advice and meaningful activities.

- Dementia Friendly Communities can help break down the stigma of the condition and allow people affected by dementia to access their community. Everyone can help to make their communities more dementia friendly and public sector organisations such as the County Council and the CCG have a particular role to play in ensuring all staff are skilled in dementia care at a level relevant to their role.
- Local Dementia Action Alliances (LDAAs) help enable Dementia Friendly Communities and these have grown considerably in the past five years with a membership of around 300 members including local businesses, community groups, faith groups, schools and colleges, libraries, museums, shopping centres and charities as well as health and social care providers. There continues to be concern over how this work can be sustained and a coordinated response to how LDAAs are supported and funded going forward is required. A sub-group is currently looking at what can be achieved within current resources and with a little funding.
- Caring for someone with dementia can put a huge strain on the carer's physical and mental health and finances. The carer needs access to information and advice, support and respite so that they can continue in their caring role together with a coordinated offer of training. Carers can also become cut off from the community leading to social isolation and resultant worsening of health. There needs to be a consistent offer of peer support, carers groups, and support to find and maintain paid and unpaid work that help them to stay connected.
- For people living with dementia there should be the offer of a range of affordable activities that are tailored to their individual needs and consideration should be given to ensuring activities are inclusive of people from diverse groups. People also need support to be able to take part in non-specialist/mainstream groups and activities or paid and unpaid work.
- Travelling to groups and activities can be challenging particularly as many people with dementia are no longer able to drive. There needs to be a robust transport plan in place and more local based provision.
- Access to information and advice about living with dementia, welfare benefits and the support available is key to ensuring all people affected by dementia can continue to live well with the condition. There needs to be a 'no wrong door' approach to the level and quality of information people can access which calls for better sharing of information.

7. Dying Well

7.1 Areas of focus for this stage of the pathway are around; ensuring people receive good person-centred compassionate care by skilled staff at the end

of their life, people being enabled to die in the place of their choosing, supporting families and carers at end of life and bereavement support and counselling.

- People should have the opportunity to plan for their end of life care along with those around them, as soon after diagnosis as possible. This reduces the likelihood that difficult and emotional decisions have to be made in crisis when the wishes of the person with dementia cannot be taken into account. Where consent is given, the plan should be shared with all those involved in the person's care.
- People nearing the end of their life need to receive coordinated, compassionate care that is individual to their needs. This includes palliative care for the person with dementia and bereavement support for carers. Care needs to be delivered by skilled staff throughout the person's life journey. Hospices can play an important role in supporting staff to care for people with dementia, as well as caring directly for people with dementia especially where the person has more than one long term condition.
- Care for one another in times of grief and loss is everyone's responsibility and supportive networks have a key role in supporting people during illness, dying and bereavement. This ambition links in with Public Health's work around Compassionate Communities.

7.2 Dementia prevalence continues to rise in line with the ageing population and it will be necessary to ensure there is continued investment in services designed to provide a timely diagnosis and ongoing care and support to ensure they keep up with the rise in demand. We also need to; enable people to reduce the modifiable risks of dementia, redesign and transform services to focus resources on keeping people independent for longer, support family and friend carers in their caring role and support a community-led approach to enabling people to live well with dementia. A delivery plan underpins this Strategy which includes objectives that can be achieved with current resources and a set of more ambitious targets that can be achieved with a little or much more funding.

7.3 We know that to really meet the needs of the individual, it is important to listen to them. We will therefore involve people living with dementia and their families in helping us achieve the aspirations set out in this Strategy and will continue to re-visit our vision to ensure the voice of lived experience not only remains central to the strategy but helps to measure the impact of it.

8. Resources

8.1 There is currently no additional funding identified for the implementation of the new Dementia Strategy. The sub-groups mentioned in this report have looked at what can be achieved with current resources and what can be achieved if there is a little or a lot more funding available in the future. These aspirations together with some estimated costings have been included with the delivery plan to be used as a basis for any future business case.

9. Factors taken into account

9.1 Issues for consideration by the Select Committee

9.2 The Committee is asked to consider the priorities within the West Sussex Joint Dementia Strategy 2020-23 around the dementia well pathway particularly the diagnosis and post-diagnostic stages. Key areas for scrutiny include:

- Plans to address priorities where little progress has been made in the previous strategy;
- Plans to address the gaps in the current dementia pathway;
- Areas of focus in relation to prevention activities;
- Diagnosis rates and future plans for the Dementia Assessment Service;
- How the consultation findings have informed the updated strategy;
- The deliverability of the high-level delivery plan;
- Plans for ongoing performance monitoring.

10. Consultation

- 10.1 An extensive stakeholder engagement took place in 2018 as part of the review of the Dementia Framework 2014-19. This comprised focus groups and interviews with people living with dementia, family and friend carers and health and social care staff; two on-line surveys for residents and health and social care staff through the "Have Your Say" online portal. In total 366 people took part in the engagement.
- 10.2 Focus groups comprising people living with dementia and family and friend carers have been consulted in the development of the new Strategy along with carers groups and the Sangam Women's group, an association of Asian women.
- 10.3 A multi-agency task & finish group comprising representatives from health, social care, district & borough councils and community and voluntary sector providers have helped drive the Strategy through. The strategy has been further shared with Local Dementia Action Alliances and internal and external partners.
- 10.4 The Strategy has been presented to the Health & Wellbeing Board, Adults & Health Leadership team, Clinical Commissioning Group's Quality Committees and LMT.

11. Risk Implications & Mitigations

Risk	Mitigation Action (in place or planned)
Strategic priorities identified in strategy are not implemented resulting in both poor outcomes and reputational risk	A Dementia Strategic Partnership Board will be established that will monitor the progress of this Strategy, identify gaps and work together to help find solutions
Strategy does not address emerging issues	Review of the Strategy in 2023

12. Other options considered

12.1 Not applicable for this report.

13. Equality Duty

- 13.1 The strategy impacts on people and groups with protected characteristics in several areas:
- Age: Although dementia can affect people of any age it is more common in people over the age of 65.
 - Ethnicity: People from BAME groups are at an increased risk of dementia, but among this population there are lower levels of awareness of dementia and high levels of stigma associated with the condition. People from BAME backgrounds are under-represented in dementia services and tend to present to services later.
 - Learning disabilities: People with learning disabilities have a higher risk of developing dementia than other people and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50s.
 - Sexuality: People from LGBT+ community are less likely to have family members and children to provide support. They are also more likely to live on their own and be single. Many LGBT+ people fear that mainstream care services will not be willing or are not able to understand how to meet their needs.

14. Social value

14.1 Not applicable for this report.

15. Crime and disorder implications

15.1 Not applicable for this report.

16. Human rights implications

16.1 Not applicable for this report.

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Appendices:

Appendix A: West Sussex Joint Dementia Strategy 2020-23
Appendix B: Dementia Cartogram
Appendix C: High level delivery plan

Background Papers - None