

Wiltshire Council

Health Select Committee

10 September 2024

Wiltshire Council and Wiltshire ICB Dementia Strategy Update 2023-2028

Purpose of report

1. To provide an update on the Dementia Strategy 2023-2028 presented to the committee in June 2023, alongside an overview of the dementia advisors and community services contracts and an update on the dementia diagnosis rates in Wiltshire.

Background

2. The word 'dementia' describes a group of symptoms that occur when the brain is affected by specific diseases and conditions, such as Alzheimer's disease and vascular dementia, amongst others. Symptoms of dementia vary but often include loss of memory, confusion and problems with speech and understanding.
3. Dementia is progressive and as it advances so do the symptoms, up to the point that people will have difficulty in undertaking everyday tasks and will need increasing support and assistance from others.
4. In Wiltshire dementia is seen as a long-term condition, although it is acknowledged that many specialist dementia services are provided by a mental health organisation (Avon and Wiltshire Mental Health Partnership) and that people with dementia may also have needs relating to their mental health.
5. Whilst there is currently no cure for dementia, there are a number of types of support that can help someone to live well with dementia. Support and treatment can also often help to alleviate symptoms or to slow the progression of the dementia for many people.
6. Within recent years there has been an increased focus on dementia at a national level due to a number of factors, including a rising older population and therefore increasing number of people with dementia coupled with a lack of awareness and understanding of dementia leading to stigmatisation and poor-quality care.
7. As a result of this, there is now a substantial body of national policy, legislation and guidance that advises and directs organisations on how to best support people with dementia and their carers and families.

8. In 2022, the Dementia diagnosis rate in over 65-year-olds in Wiltshire is estimated to be 58.5% equivalent to around 4,300 people. This indicates that there are in the region of a further 3,000 people in older age groups in the county that are undiagnosed. By 2030, it is estimated that almost 11,500 people in Wiltshire aged 65 and above will be living with Dementia, driven primarily by an aging population and increased life expectancy.
9. Younger onset dementia must not be overlooked and, although rarer, still currently affects 106 Wiltshire residents. (July 2019 figures). Recognition also needs to be given to the emergence of diverse cohorts who will need to access dementia provision across Wiltshire.

Commissioned Services

10. Within Wiltshire there are two community-based contracts to support individuals with a diagnosis of dementia and also their carers, Dementia Advisors and Dementia Community Services. Both contracts are delivered by Alzheimer's Support. The contracts with Alzheimer's Support expired on 31 March 2024 and the contract went out to tender. Following the procurement exercise Alzheimer's Support was re-awarded both contracts.
11. Both contracts are under a section 75 agreement with Wiltshire Council holding contractual responsibility. The funding is a 50/50 split. The total contract value for the Dementia Advisors £240,000. The Dementia Community service is £340,000. The contract term is a 2-year contract + 1 + 1 – i.e. potentially 4 years in total but with a break clause at years 2 & 3.

Dementia Advisor Contract

12. People eligible to use the service are people with suspected or diagnosed dementia and their carers, who are residing in Wiltshire or who are registered on the list of NHS patients of a GP surgery that is part of the Wiltshire ICB. There is no charge for individuals accessing the service which runs weekdays 9am to 6pm. Access is through self-referral/family/friends/healthcare professionals, or voluntary partners.
13. The service provides people with dementia and their carers with information, signposting and support service. The Service is delivered in a manner that ensures that it can be accessed at any point throughout an individual's journey with dementia from pre-diagnosis to end of life and that each individual has a named person as their primary point of contact.
14. The focus of the Service is on the person with dementia but includes the network of people around the person with dementia including carers and family members. The Service is delivered to ensure that the person with dementia is given the opportunity to voice their needs, wishes and views.
15. When the contract was reprocured a review of KPI's was undertaken due to the increasing aging population in Wiltshire, along with the work undertaken with the Wiltshire Dementia Strategy. In response to this a target requirement was set of a 10% increase on the number of clients year on year for the Dementia Advisor contract. In addition, the duration of support was extended to be until of

life rather than until the individual goes into a care/nursing home to ensure the service is delivered was line with the principles of the Wiltshire Dementia Strategy.

16. The service has capacity to assess 900 new people diagnosed with dementia and their carers annually. The cost per ongoing support plan is £114. Management costs are 15%.

Key elements of the service include:

17. Information - provided information to individuals who are worried about their memories about what to do and where to go. Provide information about possible causes of memory problems and about the benefits of early diagnosis and encourage individuals to seek a diagnosis.
18. Identify needs - for individuals with a diagnosis, arrange to meet them face-to-face (or/ and their carer as required) at a venue of their choice. The individual should be offered an appointment within two weeks of making contact with the service.
19. Support plan - Identify information and support needs and develop a support plan with the individual be that the person with dementia or the carer in order to best meet their needs and take into account the services that the person with dementia is already in contact with.
20. Reviews - Following the first meeting, a second meeting is arranged as required. This will include updating individuals' support plans, where contact between the service and an individual has identified a need to so do, or every six months. The plan takes into account the services that the person with dementia is already in contact with and whether their needs have changed. Following this, individuals will be contacted at least twice a year by phone and individuals will be able to contact the service whenever they have information needs. Cases remain open, ensuring that people can make contact with the service at any point in time.
21. Carers Support - included on going contact with the advisor, guidance, support and information on dementia, welfare benefits and referrals, assisting navigating dementia care, access to a 6 week Zoom carers training course, carer assessments are offered during face to face visits.

Other aspects of the Service:

22. The service attends multi-disciplinary meetings and regularly link in with: Wiltshire Council, Age UK, Citizens Advice Carer Support, Dorothy House, Acute Hospitals, Memory Service, Care Homes. Wiltshire Alzheimer's partnership Group. They undertake promoting dementia awareness/education campaigns, this has included Dementia Wristband launch, Safer and Supportive Salisbury, Calne Dementia event, A Walk to Remember, and high-profile activities (local fetes, open gardens, concerts).

23. Delivering training which includes Living with Dementia Programme, which Alzheimer's Support are licensed to deliver this award-winning two-day programme based on people with dementia lived experiences.
24. Providing access to the Dementia Roadmap which offers an online dementia 'Support Village', digital advisor service and downloadable resources.

Dementia Community Services

25. Alzheimer's Support delivers 800+ individual sessions/groups annually, with 8800+ separate attendances. The aim of the co-designed groups for clients and carers is to keep them active, reduce isolation and provide practical and emotional support. Access is through self-referral, family, friends, healthcare professionals (e.g. GPs), voluntary partners.
26. Activity groups include:
 - Memory cafes
 - Music/singing therapy
 - Movement and Exercise
 - Discussion groups
 - Art/reading/craft sessions
 - Memory shed
 - Muddy Boots outdoor gardening
 - Carers groups
27. In the new contract Alzheimer's Support aims to increase and diversify groups and activities, including flexible weekend/evening provision and to provide a minimum of 1000 group sessions annually over four areas: North/East/South/West (1100+ people, 10000+ attendances).
28. To achieve this, they will utilise their delivery team and also via flexible spot purchasing and Service Level Agreements, including "grassroots" and "micro-organisations" strengthening local partnerships, expanding reach. Arrangements include Calne Charity, Reconnecting Support Group, We Hear You, WSUN (SERVE), Celebrating Age, Salisbury Memory Group & Downton Downtime, Creating Dementia Hub Salisbury.
29. Community Service volunteers already provide 4000+ hours annually co-facilitating the wide range of groups/activities, enhancing provision, equivalent to £57500+, ensuring exceptional value and benefits beyond the contract's financial envelope.
30. Alzheimer's Support aim to build on their ongoing local community event participation, helping create "Dementia Friendly Communities", e.g., working with partners including Muse SW/Home Instead to bring the Dementia Dome to Wiltshire, an immersive experience increasing public awareness. Existing Volunteer Community Ambassadors also promote dementia communities through their participation in numerous community events every year.
31. Alzheimer's Support have a successful track record, enhancing the current Community Service, e.g. raised: £90000 over three years for the groups from

charitable foundations and fundraising. £120,000 to open a new office in Salisbury, increasing geographical presence.

32. Alzheimer's Support has a dementia partnership with Age UK, Citizens Advice, Carers Support, Dorothy House, GWH, RUN, SDH, Savernake Hospital and memory service, in addition to a dementia care initiative with Wiltshire Council, SDH, Care Homes, Community organisations, family support network.

33. As a result they:

Build in more support to:

- PWD/Families during hospital stays
- Raise dementia awareness
- Residents with dementia in care homes

Dementia Strategy

34. Dementia is one of the biggest challenges of our time. Almost one million people live with dementia in the UK and 1 in 11 people over the age of 65 have dementia. Dementia costs the UK economy £25 billion per year in terms of health and social care costs and the contribution of unpaid carers¹. In 2022, dementia was the leading cause of death in the UK². Many dementias do not yet have a treatment to prevent, cure or slow progression.

35. In Wiltshire, we have one of the fastest growing numbers of older people. Between the 2011 and 2021 Censuses, Wiltshire was one of only three local authorities in the South West whose 65+ population grew by more than 30%. This is highly relevant to the dementia strategy because age is the biggest risk factor for developing dementia, although dementia is not a natural part of ageing.

36. The vision is to create strong communities where people can fulfil their potential, be actively involved and included in their communities, make informed decisions, have control over their lives, and be valued and included within society. In Wiltshire, we start from the strengths, talents and assets that each person has – this means looking beyond their diagnosis or needs, however important these may be. This vision reflects what people in Wiltshire have told us they want in order to live well.

37. We have had some instability in the Wiltshire Council lead for the strategy, we are now on our 3rd lead in 12 months, however we now have a clear lead team consisting of Wiltshire Council Commissioning, ICB Commissioning, AWP, Public Health and Dorothy House. This core team has worked well to keep the implementation plan on track and agree on the right path forwards.

38. The strategy has been published and a strategic working group has been established to ensure the implementation plan accompanying the strategy continues to move forward and deliver on the action items highlighted within the strategy.

39. A review of the action items and a prioritisation of the key priorities with a delivery deadline has been undertaken and agreed by core team leads and the strategic working group. The key priorities update has been shared with both the TASC Operations Board and the TASC Executive Board.
40. The 8 key priorities are:
1. Creation of an awareness and signposting handbook
 2. Update and / or refresh of the information within the Wiltshire Dementia Roadmap
 3. Make it easier for people to informally think / talk about dementia
 4. Equitable coverage of dementia advisors across the county
 5. Review of accommodation provision and care professionals' skills
 6. Equitable coverage of dementia community services across the county
 7. Linking with the Carers Strategy regards training support and opportunities for unpaid carers
 8. Ensure the delivery of high-quality end of life care
41. At the last strategy working group meeting we kicked off 4 of the 8 key priorities, working to develop a timeline with key deliverables and actions highlighted. The takeaway from the meeting was for the groups to meet and complete the timeline before the next meeting on 13 August 2024.
42. In the next meeting we will kick off the remaining 4 priorities, work on developing the timelines for these priorities and reviewing the work completed since the last meeting.
43. Whilst we have over 30 members signed up to the strategic working group, we see approximately a third regularly engaging in the meetings. We have had an initial uptick in interest with the key priorities but are yet to see tangible output from the smaller working groups aligned to the priorities.

Dementia Diagnosis and Treatment

44. In 2013, a partnership initiative between AWP Mental Health Trust and Wiltshire Primary care led to the development of a Dementia Local Enhanced Service Agreement. The introduction of the LES has enabled greater assessment and diagnosis of non complex cases in primary care with support from specialist AWP clinicians. Consequently, memory clinics have been enabled to undertake more timely assessments for people presenting with more complex symptoms, often younger people or those with comorbid psychiatric conditions. Greater capacity to diagnose dementia across primary and secondary care has significantly reduced the waiting time for all people to receive an assessment and commence treatment where appropriate. Waiting times prior to the LES were understood to be in excess of 2 years.
45. Earlier diagnosis, treatment and support is associated with better clinical outcomes, particularly the use of medications which can help slow the rate of cognitive decline. The Dementia LES included a training package to support GP's in the initiation of Donepezil which significantly increased access to the recommended treatment for early / mild dementia. Access to some support

services can be diagnosis dependent, therefore delays to diagnosis can create barriers in receiving critical help.

46. AWP's memory services offer assessment, diagnosis and treatment to people with complex presentations which may include young onset, atypical symptomology or comorbid psychiatric conditions. Treatment plans can be initiated by memory service clinicians which are reviewed and optimised before transferring care back to GP's under a Shared Care Protocol. At present, the waiting time from GP referral to initial appointment with a memory nurse is approximately 6 weeks, however there can be a further wait of up to 3 months following this appointment for a consultation to confirm diagnosis and commence treatment. Making a diagnosis of dementia usually requires one or two contacts however, in some cases it may take several contacts over an extended period to correctly diagnose the specific type of dementia. Not everyone assessed under the memory service receives a diagnosis of dementia as there may be other conditions or factors affecting someone's memory or cognition.
47. Due to the demand on assessment and diagnosis appointments, the memory service has limited capacity to offer a full range of post diagnostic support interventions. Memory services work in close partnership with Alzheimer's Support to ensure people receiving a new diagnosis are referred immediately for ongoing support including carers support services.
48. For a certain cohort of people, attending memory clinic may not be appropriate or necessary, e.g. those who are particularly frail or in care homes. Coexisting frailty and physical health needs are likely to require frequent interventions from GPs and other health and social care teams. AWP are looking to support the use of an assessment tool (DiADeM) which can be useful in making a dementia diagnosis for people with advanced symptoms and frailty.

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Background papers

Appendices