

Wiltshire Council

Health Select Committee

23 September 2014

Report of the AWP/Dementia Task Group

Purpose of Report

- 1 To present the final report of the AWP/Dementia Task Group.

Background

- 2 The Health Select Committee endorsed the establishment of the AWP/Dementia Task Group at its meeting in March 2013, following concerns raised over the temporary closure of Charterhouse in Trowbridge. The formation of the Task Group was delayed due to the imminent Council elections in May but following the elections, the new Health Select Committee agreed to the inclusion of the Task Group in its work programme as a legacy item. The O & S Management Committee endorsed the work programme at its meeting in October and the Task Group had its inaugural meeting on 18 October 2013.
- 3 The Task Group was keen to consider the outcome from the three month public consultation on the draft Dementia Strategy which has delayed the production of the final report to a degree. In June 2014, the Executive requested that the Task Group undertake a piece of work on meeting the needs of people with advanced dementia in Wiltshire and the Task Group agreed to incorporate its findings within its wider report.
- 4 The questions the Executive asked the Task Group to consider were:
 - What are the key components of the care pathway for advanced dementia care which will meet the needs of Wiltshire residents? (See paragraph 48).
 - Are dementia patients able to be treated holistically for their physical needs as well as their dementia in best in class clinical settings in close proximity to one another in order to deal with their physical and their dementia needs?
 - Are there opportunities available to health and social care services that would improve the quality of advanced dementia care services for people with dementia and their carers?

- Could community interventions available to people with dementia be strengthened to diminish dependency or prevent admissions to inpatient services?

Responses to the questions are contained within the report.

Membership

- 5 The membership of the Task Group has changed over its life, with the resignation of one member and the addition of three members.

Cllr John Noeken (chairman)

Steve Wheeler

Cllr Nina Phillips (from October 2013 to July 2014)

Diane Gooch (from February 2014)

Irene Kohler (from February 2014)

Cllr John Walsh (from July 2014)

Witnesses, written evidence, visits

- 6 The Task Group took evidence from a wide range of individuals, considered a number of documents and undertook a number of visits, all of which are listed in Appendix 1.

Key findings

- 7 The Task Group amassed a large amount of information throughout its review, including what services were currently available to both professionals and people with dementia (PWD) and their carers. The following paragraphs represent a number of key findings only.
- 8 Dementia can be defined as a global change in cognitive function, lasting over 6 months. No single characteristic defines severe dementia. There are 140 different types of dementia; the two most common forms are Alzheimer's disease and vascular dementia. 10% of PWD have mixed type dementia, a combination of Alzheimer's disease and vascular dementia. A further 10% of PWD will have Dementia with Lewy bodies (DWL) which shares characteristics with both Alzheimer's and Parkinson's diseases. Other examples of related conditions in which dementia can sometimes occur include HIV related dementia, Motor Neurone Disease and Down's Syndrome.
- 9 Themes in relation to what PWD said they need and want included¹:

¹ Report on the contract to consult with people with dementia regarding services they want and need, Westminster Council 2010 and Salisbury Reference Group 2014.

- Wanting to live their lives as normally as possible for as long as possible;
 - Engaging/participating in activities that allowed them to forget they have dementia;
 - Meeting other people with dementia, not carers (in the same boat);
 - Help planning for the future
 - Social opportunities where they and their condition are understood;
 - Practical help to do what they wanted, well-meaning people could be restricting.
- 10 Other important themes included:
- Requirement for early diagnosis;
 - Needing help coming to terms with having dementia;
 - Dementia not always the most important thing in a person's life;
 - 1:1 support in the later stages of dementia;
 - Maintenance of a familiar environment in later stages.
- 11 95% of PWD have two or more morbidities. In Wiltshire there are currently over 6500 PWD, of whom, approximately 1500 - 2100 live alone. The numbers of PWD are forecast to grow by almost 30% by 2020.
- 12 In 2012/13 the diagnosis rate for dementia in Wiltshire was 36.7%. The Wiltshire Clinical Commissioning Group (CCG) invested funds and offered training to incentivise GP surgeries to increase their diagnosis rates; the rates for 2013/14 were 46%. There was a significant variation in diagnosis rates between surgeries. The national target is for 66% of PWD to be diagnosed and receiving post diagnostic support by 2015. The CCG plans to promote ongoing education and to all surgeries that require support.
- 13 An early diagnosis of dementia was important to provide maximum opportunity to plan for the future and also allowed for early medication, where appropriate. Most initial, simple diagnoses were completed by GPs. More complex diagnoses were diverted to specialist Memory Clinics. Previously there had been long waiting times for people to be assessed by the memory services but significant improvements have been made and there is no longer a wait to access the memory services in Wiltshire.
- 14 The Avon and Wiltshire Mental Health Partnership (AWP) provided a primary care liaison (PCL) service which supported GPs with diagnoses and provided them with advice to try to avoid PWD going into secondary care unnecessarily; memory services which worked with PWD requiring specialist assessment, and acute hospital liaison teams who offered mental health

assessments for adults attending A & E departments. They also provided intensive services.

- 15 The PCL service provided short-term support to help people with mental health issues to move forward and get on with their lives. PCL nurses operated alongside GPs and were specialist and experienced mental health practitioners with the knowledge and skills to decide if someone would benefit from short-term involvement with their team. Nurses delivered direct patient assessment as well as managing referrals.
- 16 Many PWD were cared for in their own homes by their, often elderly, spouse or other family member. 9 out of 10 admissions to care homes are due to carer breakdown or the PWD suffering a fall.
- 17 PWD who were admitted into an acute hospital were more likely to stay longer than an average patient and became more unwell the longer they stayed. The average stay in a specialist inpatient hospital for people with advanced dementia is currently 84 days. At present people with advanced dementia were more likely to be discharged into a nursing home than return home with a package of care.
- 18 Patients were being treated holistically for their physical needs and dementia needs. All three acute hospitals that serve Wiltshire had undertaken significant work in relation to the elderly and PWD creating dementia friendly wards and recruiting 'dementia champions'. One acute hospital had secured significant funding from the Department of Health to support this work. The Task Group wished to congratulate the acute hospitals on this work aimed at improving the quality of care for PWD.
- 19 There were currently insufficient residential placement beds in the community for people with advanced dementia. Private care home providers were often reluctant to accommodate PWD. However, the Orders of St John (OSJ) had embarked on a programme of new building to replace most of their existing homes and the Council had commissioned a number of 'dementia beds' in a number of the OSJ homes being built.
- 20 There was a national shortage of geriatricians and registered nurses. One acute hospital indicated that community clinics for elderly people were limited due to lack of geriatricians. The acute hospitals serving Wiltshire were recruiting nurses from Ireland, Spain and Portugal. AWP encountered difficulties in recruitment. There was also a shortage of approving doctors under section 12 of the Mental Health Act 1983, particularly at the week-ends.

- 21 Under the Care Act 2014 the Council must arrange an independent advocate to facilitate the involvement of a person in their assessment, in the preparation of their care and support plan and in the review of their care plan if the following two conditions are met. The aim is to provide assistance to a) people who had substantial difficulty in being fully involved in these processes and b) where there was no one appropriate available to support and represent the person's wishes.
- 22 The CCG spent approximately £7.5 million in 2013/14 on dementia initiatives, some of which were jointly funded with the Council. In 2013/14 the Council spent £14.8 million supporting PWD and their families and carers. £14.2 million was spent on care packages and placements and £0.1 million was spent on a dementia environment project. £0.5 million was allocated to the Alzheimer's Society, covering N and S Wiltshire, and Alzheimer's Support, covering E and W Wiltshire.
- 23 Both Alzheimer's organisations contributed additional funding from their own fund raising resources as well as extensive volunteer time. They provided a range of services for PWD and their carers including Alzheimer/memory cafés, day clubs, advice/courses for carers, movement for the mind and Singing for the Brain®.
- 24 They also provided the Dementia Advisor Service which was commissioned jointly by the Council and the CCG. Eight Dementia Advisors provided information and signposting to PWD and/or their carers. 881 referrals were made to the service in 2013/14, with 752 information support plans created.
- 25 From our discussions, there appears to be some confusion among GPs, practice managers and other primary care staff over the roles of Dementia Advisors and Care Coordinators, both clinical and non-clinical, which needed to be addressed.
- 26 NICE guidance recommended that people with mild-to-moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme, irrespective of any drug prescribed for the treatment of cognitive symptoms of dementia. Cognitive Stimulation Therapy (CST) aimed to actively stimulate and engage PWD through a series of sessions of themed activities. Practitioners such as care workers, occupational therapist and nurses could learn to provide CST treatment for PWD. CST was evidence-based and was shown to be more cost-effective than usual care when looking at benefits in cognition and quality of life. Recent information indicates that an Alzheimer's organisation had submitted a proposal for consideration by the Council and the CCG with respect to running a CST pilot, which the Task Group welcomed.

Advanced dementia findings

- 27 At times of crises, a small number of people with advanced dementia (no more than 120 people over a year) would require a specialist inpatient bed due to concerns about safety to themselves and others. However, such crises were often as a result of physical ailments and/or the dementia itself, most especially as it progressed, coupled with an issue related to the carer e.g. heart disease.
- 28 AWP had a 20 bed unit (Amblescroft South) at Fountain Way, Salisbury which accommodated people with organic (dementia) mental health problems. These 20 beds (Amblescroft South) were available for people with profound dementia and behavioural difficulties; admission was based on safety and risk criteria. It was likely that people with advanced dementia who had been admitted to Amblescroft South would require ongoing specialist nursing care. It was reported that the figure for 'delayed transfers to care' at Amblescroft was higher than the national average.
- 29 On the day of the visit to Amblescroft the Task Group observed that it provided a calm, intimate environment for people with advanced dementia. It offered a high level of care and support and appropriate activities for which it was to be commended. It was located within a short distance from Salisbury District Hospital (approximately 4 miles), should medical attention be required.
- 30 Care home placements, with the high level of clinical care required for people leaving Amblescroft South, were made in specialist residential/nursing homes out of the county at considerable cost. This could result in 'delayed transfers to care' at Amblescroft South, as family members were reluctant for their relatives to be placed too far from home; transport for visiting could be difficult and the placement was likely to be for the remainder of the person's life.
- 31 However, discussions between the Council and OSJ were currently underway to allocate a number of beds within OSJ's new care homes to those people leaving Amblescroft South. Resources would be committed to provide the high level of care required by people with advanced dementia; numbers for which are forecast to increase over the next 10 years.
- 32 AWP had acute beds in other localities which were commissioned by neighbouring local authorities. There was a reciprocal arrangement whereby if it was more convenient for a Wiltshire person to be accommodated in, say, Swindon, this could be arranged. Likewise a person from another authority may be accommodated in Amblescroft South. Allocation of beds between local authorities was managed by AWP.

Conclusions

- 33 Whilst welcoming the Dementia Strategy, it was a moot point that the issues raised by the Task Group at the Health and Wellbeing Board meeting in May 2014 had not been acted upon. Concern was raised at the Health and Wellbeing Board that the commissioning Action Plan did not accompany the Dementia Strategy. It is now understood that the Action Plan will be signed off by the Joint Commissioning Board.
- 34 The appendices of the draft Dementia Strategy highlighted the range of activities currently available and indicated some gaps in provision. The Chairman of AWP and the Vice Chairman of the Health Select Committee were informed at the Health and Wellbeing Board that no additional funding would be made available for dementia and that, following the public consultation, the final draft Dementia Strategy would clearly indicate its priorities. The Task Group understood that this is work in progress. It was concerned that the programme of work proposed was unrealistic without further investment, and because of the difficulties in recruitment identified in some areas of dementia-related work. It was crucial that any intended savings from advanced dementia care were channelled into preventative care (Illustration of Prevention/Intervention: Appendix 2).
- 35 The Council and the CCG had developed a number of strategies over recent months and had a great deal of data showing projected demand; it was not always clear how these were driving commissioning decisions. The strategies had created a large number of work streams, generating extensive discussions. The Task Group was disappointed that some of these had yet to result in any action on the ground and would like to see more progress made. It was a moot point whether, within the Council, all teams dealing with dementia care should be dealt with under one head of service and a review needs to be carried out to that effect.
- 36 A project on black, Asian, and minority ethnicity (BAME) communities had been undertaken by a student seconded to the Council. The Task Group suggested that local authorities with larger BAME communities than Wiltshire were approached for more comprehensive information. It would also like to see a more developed programme of work to tackle 'hard to reach' groups.
- 37 The Task Group supported any activity provided/commissioned by the Council and the CCG that resulted in PWD receiving an early diagnosis but also acknowledged that individuals should be encouraged to be proactive in respect of their own care. This should be facilitated through continued public education and the promotion of health checks and assessments as symptoms

were observed. The Task Group would like to see evidence that the public health team is targeting funding specifically on PWD. (Appendix 3).

- 38 Whilst welcoming any work to raise awareness of dementia, the Task Group was disappointed that Wiltshire has chosen to create its own branding (Before I forget) for its community dementia toolkit. Comments made by various organisations and individuals noted that it would have been preferable to adopt the nationally recognised logo (forget-me-not flower) and that the toolkit had missed an opportunity to promote high profile national initiatives, such as Dementia Friends, and to signpost to tested national resources within the toolkit. It was also considered that the toolkit highlighted significant challenges but offered little practical advice on how to tackle them, and that liaison with the Alzheimer Society and Alzheimer Support in Wiltshire over the content of the toolkit may have resulted in a more useful document.
- 39 The Task Group supported the aims outlined in the community dementia toolkit but was concerned that some of the areas for action were not within the power of a community to deliver e.g. 'ensure an early diagnosis', 'provide consistent and reliable travel options'. It would wish to see a county-wide Dementia Action Alliance (DAA) set up in Wiltshire to which each area board could send a representative and which would facilitate the dissemination of awareness raising information and resources and encourage the sharing of experiences and ideas. The voluntary sector, the Council, the CCG and other stakeholders could input to the central Wiltshire DAA so that local communities would benefit from wider support whilst retaining ownership of individual projects and avoiding each community 're-inventing the wheel'.
- 40 A range of training initiatives were being delivered e.g. to housing and leisure centre staff. However, there was a requirement for both the Council and the CCG to extend training further to family members, carers and staff, who may encounter PWD in their daily lives and in the course of their work. A recent Care Quality Commission (CQC) report revealed serious shortcomings in respect of training, with staff receiving no training over a two year period. The work being undertaken with existing care homes to increase their training and confidence in supporting dementia patients was commended, and the Task Group would like to see the AWP care home liaison team extending this to all care home staff to ensure consistency across them.
- 41 All professions agreed that early diagnosis and early intervention were essential for PWD; the Task Group concurred with this view and believed that the Council and the CCG should maintain a focus on these areas of work. They acknowledged the difficult financial climate but, again, believed that there must be more investment in these areas (early intervention services/crisis management) to both improve the quality of life of PWD and

their carers and to retain their independence and maintain them in their homes for as long as possible.

- 42 Once a person was diagnosed with dementia, their GP was required to record them on a register which included a number of different codes against which the person could be entered. For example, many PWD may first be diagnosed with mild cognitive impairment (MCI), which was an intermediate stage between the expected cognitive decline of normal ageing and the more serious decline of dementia. The CCG was promoting the use of a targeted number of codes to ensure a specific and accurate diagnosis e.g. vascular dementia. The Task Group supported this initiative to ensure that a person was correctly recorded and that they received the necessary support as a result of early diagnosis.
- 43 Following diagnosis, planning was essential to enable PWD and their carers to make decisions about their future. It was particularly important to make plans before a crisis arose to ensure that the wishes of PWD and their carers were understood. PWD were reported to settle better, and have a better quality of life, if they had been consulted in advance of such crises arising. The Task Group agreed that independent advocates, trained in communicating with PWD, had a key role to play in assisting PWD and their carers in the preparation of their care and support plan and in planning for the future. Further, that the support of independent advocates was particularly important for PWD who lived alone, estimated to be 1500 – 2100 in Wiltshire. Some crisis plans were in place and the Task Group would like to see these rolled out across the county.
- 44 The Task Group acknowledged that there are some excellent initiatives around the county to support PWD and their carers, including Alzheimer/memory cafés, day clubs, advice/courses for carers, movement for the mind and Singing for the Brain® as well as the development of dementia friendly areas and work being undertaken by the area boards, but with numbers of PWD increasing, there were not enough and the geographical spread of services was patchy; some day care centres had a waiting list. People living alone, especially the lonely and isolated, often lacked support from their communities. The Task Group would like to see equity of access to community/support services, particularly in more rural areas where social isolation could be exacerbated by lack of transport.
- 45 The value of carers, in maintaining PWD in their own homes, should not be underestimated. Adequate support for them was essential, especially as many were elderly and it was often as a result of frailty, an illness or a fall in relation to the carer, that the PWD was hospitalised or required specialist

support. NICE guidance required that carers of PWD should have access to a comprehensive range of respite/short-break services which met the needs of both the carer (in terms of location, flexibility and timeliness) and the PWD and should include, for example, day care, day- and night-sitting, adult placement and short-term and/or overnight residential care.

- 46 With the projected increase in numbers of PWD, provision of additional support services for their carers was paramount. Without someone to look after their relative with dementia, carers were often not able to attend support activities designed for them therefore additional separate activities for PWD must be provided to give their carers the opportunity to attend. Support should also include transport to enable PWD and their carers to participate in activities.
- 47 Further consideration should be given to the support of carers who may experience psychological distress and negative psychological impact and its inclusion in the Dementia Strategy Commissioning Action Plan. Carers who have issues should be picked up through the carer reviews at surgeries and given access to NHS provision.
- 48 A study by University College, London showed that approximately 40% of carers who looked after a PWD were clinically depressed or suffered from anxiety. The amount of £0.5 million (from a total of £14.8 million) provided to the voluntary sector to support PWD and their carers was considered inadequate. Many of the ideas for promoting prevention were originating from the voluntary sector. They also needed to be encouraged and supported to access additional streams of funding, for example, SWAN Advocacy was recently successful in obtaining funding from the Lloyds Banking Group.
- 49 The Task Group wished to congratulate the acute hospitals on the efforts they had made in creating dementia friendly wards and devising systems to support the timely return of PWD to their place of residence (when appropriate) following admission to hospital.
- 50 As PWD, including those with advanced dementia, were more likely to be discharged from an acute hospital into a residential home than return home with a package of care, more work needed to be undertaken prior to discharge to investigate the full range of options available to avoid unnecessary long term admissions to care homes.
- 51 The Task Group had not been able to fully investigate clear care pathways for people with advanced dementia, due to time constraints. However, services for those people with severe learning disabilities and dementia were

commissioned by the CCG, separately from the AWP contract. The Task Group would like to see services developed so that people with severe learning disabilities were not treated separately, and services were dovetailed with those for dementia. Those undertaking health checks for people with learning disabilities should be aware of the increased risk of dementia in this group.

- 52 The Task Group had not been able to look specifically at end of life care but believed that consideration must be given to early discussions with PWD to ascertain their views while they have the capacity to do so, that mechanisms should be in place to ensure that the wishes of PWD, especially those without a carer, are fulfilled at end of life and to ensure that PWD have the same access to palliative care services as those without dementia.

Advanced dementia conclusions

- 53 The Task Group acknowledged the benefit of the current reciprocal arrangement with neighbouring local authorities over the use of advanced dementia beds, and welcomed the moves being made to accommodate people with advanced dementia within the county. Not only would this be more convenient for carers wishing to visit their relative with dementia, but it would also reduce the significant level of spending on out of county placements and release funds for more community/preventative projects. However, whilst it welcomed the discussions with OSJ about the provision of advanced dementia beds, it acknowledged that they would need to be supported by specialist nursing care and that this may be difficult due to the national recruitment issue.
- 54 As PWD often have two or more co-morbidities, the Task Group believed that any specialist inpatient provision for people with advanced dementia should be located close to an acute hospital to deal with all physical issues.

Recommendations

The Task Group recommends that:

- 55 There is a movement in funding from long term treatment packages (specialist hospital and placements) to community/preventative work including greater support for carers to reduce crises arising, and that the Council and the CCG should review their funding to facilitate this. Whilst acknowledging that some generic services may be used by PWD and their carers, that funding for dementia is retained as a separate stream.

- 56 Public health and other generic services should consider identifying a specific funding stream for WD and their carers.
- 57 As in 2013/14, the CCG should continue to use the dementia Local Enhanced Service (LES) and Directed Enhanced Service (DES) in 2014/15 to reward GP practices for undertaking a proactive approach to the timely assessment and treatment, where appropriate, of patients who may be at risk of dementia. Also that the CCG makes its best endeavours to achieve the national diagnosis rate.
- 58 The CCG continues to promote the use of a targeted number of dementia codes to record a specific diagnosis of dementia, and that once a diagnosis of dementia has been given, the GP, where necessary, provides a written statement of this to the PWD and their carer, although this is not mandatory, thereby providing important data relating to the specific diagnoses while also facilitating any claims for benefits.
- 59 The CCG considers how it will identify those people at risk of dementia, but who will miss the opportunity for an early diagnosis as they do not/rarely visit their GP.
- 60 That the Council and the CCG ensure that the dementia pathway, as described in the Action Plan, is mutually agreed. And that the commitment to involve the voluntary sector is maintained.
- 61 More focus is given to support for carers; adequate day care facilities should be provided across the county, and extended where necessary, to ensure that all carers had access to regular respite, should they require it.
- 62 Plans are developed to ensure that any support provided to carers at a time of crisis is readily available to them. To that end a route map should be developed which advises the carer of the actions they can take to access support for themselves and the PWD at a time of crisis. In addition, a similar route map should be prepared for professionals e.g. the police, who might encounter a PWD in crisis, so that they also know who to contact.
- 63 Carers who have to visit relatives who have been an inpatient in an acute dementia ward should, where possible, receive funding to enable them to visit their relative if they are placed in a residential home out of the county, until placements are available within Wiltshire. The suggested level is once a week; also that the carer retains the ability to book the transport themselves, thereby ensuring that individual requirements e.g. a wheelchair, are

accommodated. It is intended that this will encourage carers to agree to their relatives being placed in suitable accommodation in more distant locations.

- 64 That, following the CST pilot, the Council and the CCG should consider initiating a project with a view to funding and providing Cognitive Stimulation Therapy for people with mild to moderate dementia.
- 65 The Council considers making funding available to guarantee that there is sufficient provision of independent advocacy to ensure that it meets its statutory obligations under the Care Act 2014 and also maintain the generic service.
- 66 Officers in public health, the commissioning teams in adult social care and the specialist commissioning team in the Council meet together on a regular basis to take forward the dementia work to ensure effective liaison.
- 67 In developing their plans for PWD and their carers, the Council and the CCG should take account of the conclusions drawn by the Task Group in its review in paragraphs 33 to 54 above.
- 68 After a period of 2 years, the Task Group should re-form to review progress to ensure that, at a minimum, the actions identified in the commissioning Action Plan 2014-15 have been delivered.

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Appendices

Appendix 1 List of witnesses, written evidence and visits undertaken by members of the Task Group

Appendix 2 Prevention/Intervention triangle

Appendix 3 Funding for public health prevention programmes that contribute to the reduction in risk of developing dementia