Agenda Item No. 5

Health and Adult Social Care Select Committee

3 October 2013

Dementia Services

Report by Head of Public Health and Health & Social Care Commissioning

Executive Summary

This paper is to inform the Health and Adult Social Care Select Committee (HASC) of the extensive work that has taken place to develop dementia services in West Sussex since it last reviewed these services in 2011. The paper will update the Committee on progress, priorities and the challenges ahead.

Since the last scrutiny of dementia provision, a number of new services have been implemented providing support to people with dementia and their families/carers, including, including Memory Assessment services , dementia crisis teams, care home in-reach and the Shared Care Ward at Princess Royal Hospital. Challenges include demand from a growing population and a higher number of people diagnosed at an earlier stage in the pathway; financial pressures in the context of higher demand for services; and breaking down the stigma of dementia in order to normalise and promote services.

Priorities for service commissioners and providers include the integration of services to ensure there is a pathway of care that looks at the whole person rather than their individual illnesses or circumstances; the development of Dementia Friendly Communities; and a new dementia strategy, due to be completed by February 2014.

Recommendations

The Committee is asked to review dementia services in West Sussex and to:

1. Evaluate the impact and take-up of the Memory Assessment Service;
2. Review the effectiveness of measures to improve the rate of dementia diagnosis in West Sussex;
3. Identify any areas for service improvement and/or issues for further scrutiny by this Committee; and
4. Agree any recommendations it wishes to make to the relevant organisations (NHS Trusts, West Sussex County Council Cabinet Member for Health and Adults' Services)

1. Background

1.1 Dementia is a key focus of both health and social care nationally, with the Prime Minister announcing the Dementia Challenge, highlighting the need for –

- **An integrated care response** – services can no longer be viewed as 'health' or 'social care' but instead be focussing on the whole person rather than condition specific care.

- **Dementia friendly communities** and tackling stigma – local towns and villages should be educated to understand dementia and the challenges someone living with dementia can encounter in their everyday life. From this, the stigma associated with dementia can be broken down, local support networks can be developed and people living with dementia can play a key role in their community.

- **Improving diagnosis rates** - An early diagnosis can link people with dementia and their families into vital support networks, improving quality of life, minimising the likelihood of a crisis and allowing people to plan for their future needs.

1.2 The number of people over 65, and the prevalence of dementia in West Sussex is higher than average, with a rise of approximately 20% expected by the year 2020. Currently, there are approximately 13,778 people living with dementia, in 2020 there will be approximately 16,175. In the context of a growing population and shrinking statutory resources, the dementia challenge in West Sussex is significant. However, there is also have a strong statutory focus on dementia from both health and social care leads, as well as a strong third sector presence across the county.

2. The services

2.1 Dementia crisis service

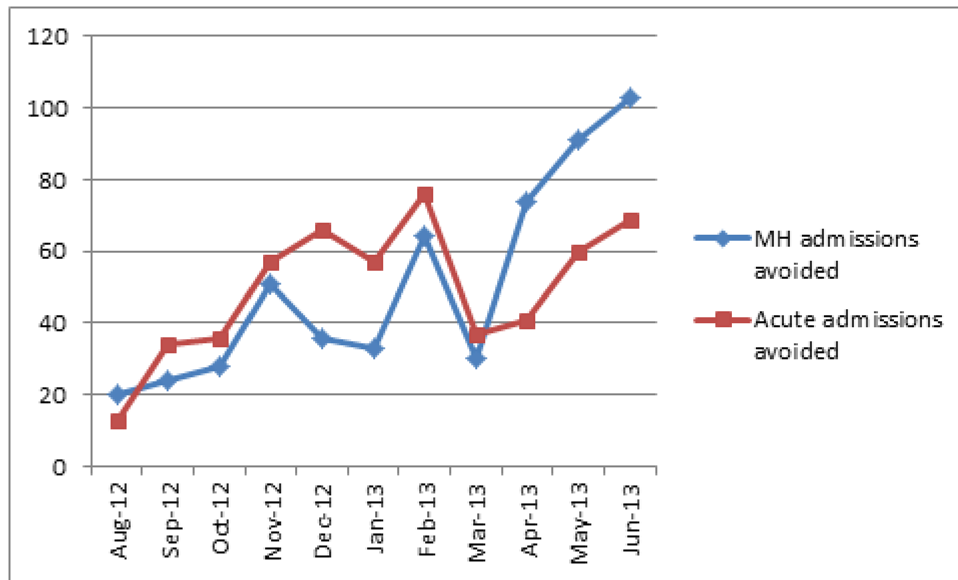
2.1.1 Multi-disciplinary Dementia Crisis teams are now operational across West Sussex. The service provides urgent assessments to ascertain whether an intensive time limited (maximum of 6 weeks) community support package could prevent a hospital admission or further deterioration. Each team includes psychiatry and nursing and operates in active partnership with Adults' Services and a home care agency to provide an integrated response to crisis. This includes access to:

- Intensive psychiatric and nursing support throughout the crisis period and referral onwards to appropriate services.
- A short-term specialist home care team who can provide 1:1 care in the home for a period of 72 hours, including overnight
- A crisis bed in a residential care home providing specialist dementia care (maximum 72 hours)
- On-going care for up to six weeks in partnership with local home care agencies.
- Signposting families to community and third sector support, for example Alzheimer's Society, Carers Support Service.

2.1.2 The teams also act as the 'gatekeepers' for mental health beds – they will assess anyone who is to be admitted in order to ascertain whether a community based intensive support package could avoid an admission.

2.1.3 The teams are now working closely with the Clinical Commissioning Groups (CCGs) urgent care teams such as the RAIT (rapid access and intervention team) and AAT (admission avoidance team) in order to provide an integrated response to crisis.

2.1.4 The below graph shows the steady increase in admissions avoided by the crisis teams.



2.1.5 The service will be reviewed by commissioners this year to ascertain what service improvements and changes are needed after three years in operation.

Customer vignettes

"We are both so grateful for the kindness and support of the Dementia Crisis Team when we were in such trouble with M. before the bladder infection was diagnosed. The ongoing help given by A. (team member) has had a comforting and stabilizing effect on M's condition, especially whilst our daughter was away on holiday. It would not have been easy to manage the problem without the team's intervention….Because M's condition is inevitably deteriorating, further care at a higher level may become necessary, and I am grateful for your offer of contact in the future….Again, many, many thanks for all that has been done by your excellent team to help us in our personal crisis" (Spouse of patient)

"Thank you to all the staff of the Dementia Crisis Unit who helped me and my wife through our recent problems. Even the Queen and Prince Philip could not have had better attention and care than the DCU gave us during this difficult period" (Patient's spouse)

2.2 Care home in-reach team

2.2.1 The care home in-reach (CHIR) team was commissioned in 2011 and provided by Sussex Partnership Foundation NHS Trust (SPFT). The team

provide a proactive service to care homes, working with the whole home and the individual customer to embed quality dementia care. The team –

- Undertake specialist reviews of a resident, particularly if a care home is having difficulty caring for residents with a growing complexity of need.
- Use person centred techniques such as dementia care mapping in order to understand the person's behaviour and undertake joint care planning with the resident, GP and care home staff.
- Undertake reviews of medication, with a particular focus on antipsychotic medication in order to understand whether there are non-pharmacological interventions which could work better for the resident.
- Assess the home and make suggestions for changes which could enable the development of a more therapeutic environment
- Offer free training to home staff in areas such as meaningful occupation, antipsychotic medication, behaviour that challenges and person centred care

2.2.2 As with the dementia crisis service, the care home inreach team is also working towards integration with physical healthcare teams, with a focus on joint assessments and potentially joint training.

Case example -

W has been resident in a nursing home for two years and has a diagnosis of vascular dementia as well as epilepsy. He has a history of aggression and hitting out at staff and has been managed through the use of anti-psychotic medication.

CHiR became involved with W as the home reported that over a 2 -3 week period this behaviour had worsened. It was reported that he was extremely challenging and physically hostile during any personal care interventions. It was unclear how much of his prescribed medication he was taking. A number of falls had been reported over the past few months

The care staff at the home did not feel they had the skills to manage his needs appropriately and so contacted his GP who then requested a Mental Health Act assessment with a view to admission to the mental health unit. The OT and Psychiatrist from CHiR reviewed W's presentation and advised on a range of non-pharmacological interventions (e.g. use of visual aids when supporting personal care, using sensory stimulation).

The care staff were advised by CHiR on the importance of taking time and not rushing W when engaging in activities or communicating, using a quiet and soft approach until rapport established, and to recognise and record the positive behaviours and interventions found to be effective.His room appeared uninviting and lacking in stimulation so CHiR supported staff to add tactile items and rummage boxes.

On follow-up visits, the nurse in charge of the home reported that he was not hitting out as much during personal care since they introduced reminiscence conversations as a distraction technique, that he appeared more relaxed and

calm.

Staff identified that at times their verbal communication, body language and facial expressions were a trigger to his challenging behaviour as at times it made him feel threatened or like he was being told off.

Following advice from the OT, the nurse in charge had advised the care staff on appropriate ways of communicating and since implementing this he had been more responsive to care.

Following completion of the PAIN-AD , it was advised that W take regular pain killers, and he was taken off his anti-psychotic medication. The nurse in charge reported that since all the medication had been changed and there had been a change in staff approaches, there have not been any further reported incidents of aggression. She also reported that he is pacing less, less restless, able to engage in conversations and activities better, mobility has improved and there have been no further reported falls.

W was not assessed under the Mental Health Act, was not admitted to an acute Mental Health hospital bed. He has been discharged from the care of the CHIR Team as the care staff at the nursing home now feel confident in providing non-pharmacological interventions in a person-centred way, which are individual to the needs of all residents at the home.

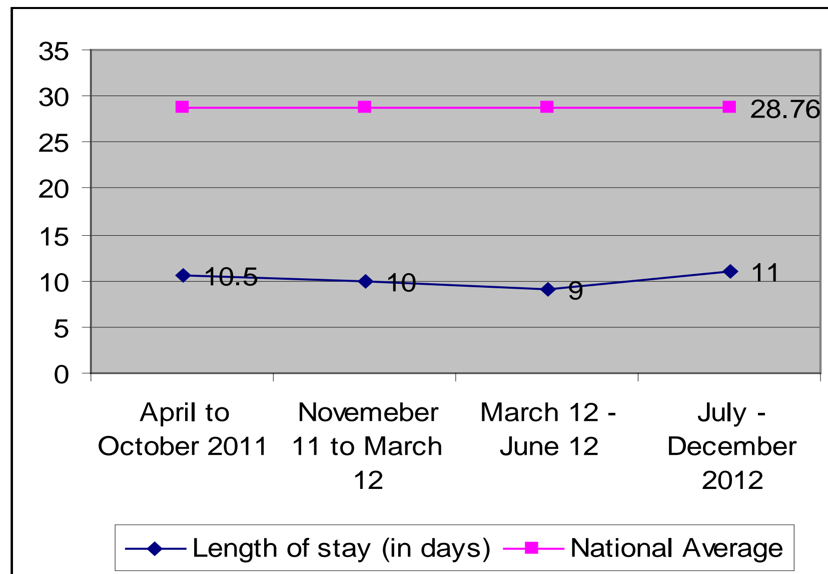
2.3 The Shared Care Ward – Poynings Unit at Princess Royal Hospital

2.3.1 The Poynings Unit was commissioned in 2011 and provided with a partnership between Brighton and Sussex University Hospitals Trust and SPFT. The ward is focussed on caring for people who have come into Princess Royal Hospital (Haywards Heath) with an acute illness or injury, but who also have moderate to severe dementia. Due to the size of the ward, it works with the patients who have the most complex and challenging behaviour.

2.3.2 The ethos is to provide a joint mental health and physical health response to the patients. The ward is staffed by an experienced team of doctors, nurses and therapists. The environment has been adapted in order to give patients a quieter, more spacious bed area, as well as areas such as a reminiscence room and day room where group and individual therapy sessions take place.

2.3.3 There are regular activities on the ward such as singing, tea parties and reminiscence. Carers and family members are encouraged to participate and contribute to their loved-ones care should they wish to do so.

2.3.4 The ward has demonstrated a significantly shorter length of stay when compared to the national average for hospital stays for people living with dementia.



2.3.5 The ward has also demonstrated significant quality and wellbeing outcomes for patients, leading to national and international interest in the model. Below is an example of a patient journey on Poynings.

Case Study

T is a 92yr old man who was admitted to the Princess Royal Hospital with bilateral leg oedema and chronic cardiac failure. He has a diagnosis of Alzheimer's Dementia and a history of macular degeneration, hiatus hernia and atrial fibrillation.

Initially he was admitted to Balcombe ward. He did not settle or respond well to this busy, noisy environment. He was attempting to leave the ward and becoming distressed. The ward was considering specialing him.

The Occupational Therapists assessed T for a bed on the Poynings Unit and he was transferred the day after admission. He was welcomed to the ward by a member of the nursing staff with a cup of tea and settled in the quieter four bedded bay. The nursing staff had the time to calmly offer him repeated reassurance about the reason for his admission and the treatment planned. He became more settled, accepting the reasons for admission and agreed to be recannulated to receive the IV diuretics he required. He also agreed to take his oral medication.

The next day T continued to settle onto the ward. His overall communication improved and, although continued to state not to want to be in hospital, he was thankful for the care he received. Ward staff completed 'Reach out to me' with T and his son and friend, which gave staff information about his background, routine as well as likes and dislikes.

Ward staff helped T orientate to the ward to improve his independence and tried to accommodate routine and likes and dislikes as much as possible. Ward staff, including the OT used the information from 'Reach out to me" to communicate and understand T, engaging him in more meaningful activities and

conversations.

OT assessment from initial admission and T's participation in group work meant that his functional ability and risks around discharge were assessed from the beginning and a timely discharge plan was developed.

2.4 Mental health Liaison teams

2.4.1 Older People's Mental Health Liaison (OPMHL) Services in the general hospital are now operational across West Sussex as advocated by NICE and the National Dementia Strategy. These services provide rapid specialist mental health assessment, support and advice for older people with a diagnosis, or suspected diagnosis, of dementia or functional mental illness admitted to acute hospital care.

2.4.2 It is well evidenced that clinical outcomes for people with dementia are poor in hospital, that lengths of stay are longer, and that they are more likely to be discharged into an increased level of care than people without dementia. The OPMHL service aims to address this though providing assessments (such as risk, mental health, capacity) and care planning for individual patients, as well as providing specialist advice and training to the acute workforce and raising awareness of the needs of people with dementia.

Case Example

A gentleman with vascular dementia was admitted to Worthing with sepsis due to a UTI[1]. As he was displaying increased agitation and aggression, a referral was made to the team. The liaison team assessed the patient and reviewed and changed his current psychiatric medication. We worked with the ward to develop non pharmacological interventions within their 1:1 nursing, using the "knowing me" document. We explained that the gentlemen preferred his personal care to be done by a male staff member instead of a female, and we encouraged the ward staff to use the activity box and allow the gentleman to go for walks around the ward. With these interventions, and the sepsis resolving, the patient was able to return home when medically fit with a package of care and community mental health input.

2.5 Memory Assessment Service

2.5.1 Memory Assessment Services (MAS) were set up throughout West Sussex in September 2012 in a partnership arrangement between SPFT and the Alzheimer's Society, with the aim of providing a comprehensive assessment, diagnosis and post diagnostic support and treatment service. This is delivered through multi- disciplinary teams consisting of psychiatry, dementia nursing, occupational therapy and psychology from Sussex Partnership and dementia advisers and support workers from the Alzheimer's Society.

[1] *Urinary tract infection*

2.5.2 MAS is an inclusive service for people of all ages, including those with a learning disability. There is a clear pathway for people worried about their memory:-

- Referral to the MAS comes from the GP after initial screening to rule out physical causes for confusion and memory loss.
- Pre-diagnostic counselling is offered and an assessment of capacity to assent undertaken where necessary.
- People are seen in a nearby clinic or at home, depending on need
- Specialist Trust staff employ a range of diagnostic tools in line with NICE guidance, including history taking, standardised cognitive screening, CT and MRI imaging, physical examination, risk assessment and more specialist neuropsychological or functional assessments as required.
- Carers are also offered an assessment of the impact of caring. A direct referral route to carers support service has been suggested and will be analysed as part of a planned yearly review of the service.
- Diagnosis is delivered by a senior clinician from the team and care is taken to break the news well and ensure the person has all the information they need.
- Every person given a diagnosis of dementia and their carer are offered a Dementia Adviser to provide information and advice about the range of local services, resources and benefits available.
- A written care plan is developed for each person, identifying the range of interventions and support that will help them through their dementia journey.
- The service provides a comprehensive package of support post diagnosis, which may include, for example, initiation of medication for cognition, access to psycho-educational groups for the person and their carer, cognitive stimulation therapy, environmental adaptations, systemic therapy, access to research trials and so on. There is also on-going support by a dementia support worker, which will be described below.
- Carers are also offered a range of interventions to support them with their caring role such as training, information on local support services and psychological therapies if required.
- Although most people use the service for about 6 months to 1 year and any prescribing passes back to the GP after this time, people with dementia and their carers are able to contact the service at any time should they need to.

2.5.3 Diagnosis levels are reported to members every quarter via the PERFORM reporting system. In quarter one of 2013 - 2014, the diagnosis rate across West Sussex was at 47% compared to the agreed Total Performance Monitor target of 45% by March, 2014. This means that currently 47% of people with dementia have a diagnosis in West Sussex. This shows the significant impact on diagnosis levels that the service has had.

2.5.4 The service is about to undergo its planned one year review. This will look at all areas of performance, address current issues (such as demand and capacity) and get feedback from primary care, people living with dementia, adults services and other stakeholders. There has been on-

going work to engage GPs both prior to service set-up and through attendance at primary care engagement events.

2.5.5 All three MAS teams are currently pursuing national accreditation with the Memory Services National Accreditation Programme (MSNAP). This is a quality kite mark provided by the Royal College of Psychiatrists and is a key recommendation of the 2010 All Party Parliamentary Group on Dementia report "Unlocking Diagnosis".

2.5.6 Currently, 97% of people wait 4 weeks or less for their initial appointment. Demand for the service does mean that waits between the initial assessment and the diagnosis appointment are lengthening. This will be addressed as a key part of the MAS review.

2.6 Dementia advisers, CRISP and on-going support

2.6.1 This dementia diagnostic service involves Alzheimer's Society directly working alongside the Sussex mental health trust, SPFT in the delivery of the service. Alzheimer's Society's contribution is to provide one dementia support manager, four dementia advisers and four dementia support workers. The staff are an integral part of the multi-disciplinary team delivering the service. Alzheimer's Society have also been contracted to deliver the Carers Information and Support Programmes (CrISP), as a key element of support to carers following the diagnosis process.

2.6.2 Alzheimer's Society staff (a Dementia Adviser and Dementia Support Worker) work within a dedicated clinical team in Memory Clinics attached to each base. These clinics have been established at a variety of locations such as GP surgeries, existing clinics and community centres.

2.6.3 Dementia Advisers (DAs) are present at Memory Clinics and are able to offer immediate advice to those newly diagnosed – they provide a framework for both the person with dementia and their carer to use to plan, as far as possible, how they would like to be supported during the progression of the disease.

2.6.4 Dementia Support Workers (DSWs) give longer-term support, information, guidance and signposting to other services - particularly through difficult periods as the disease progresses. The DSW can further support service users with practical matters e.g. supporting a service user to make a weekly diary or other memory prompt; support to write a letter. A DSW can provide emotional support to a service user e.g. help with coping with feelings of guilt. Additionally the DSW facilitates Carer Support Groups – which offer peer support to groups of between 8 to 12 individuals.

2.6.5 Dementia Advisers and Support Workers provide service users with the information they need, for them to understand and support themselves in their situation. This can include information about diagnosis, all aspects of living with dementia, legal rights, welfare benefits, national and local services and contact information. A DA/DSW can give more specialised information, after assessing and identifying individual information needs – but cannot recommend a specific course of action but may suggest a

number of different options to a service user. A DA/DSW will refer a service user on to other services only with the recorded agreement of the service user; however they would not make a direct referral to or endorse a commercial enterprise – eg a solicitor or local trade person.

2.6.6 So far in West Sussex there have 1,225 people with dementia and 389 carers supported by the Dementia Advisers and Dementia Support Workers within MAS.

Case study

Mrs R was diagnosed with Alzheimer's disease. She was suffering from anxiety and becoming isolated and because of this, not wanting to go out at all. Her husband was finding it difficult to accept the diagnosis and therefore not supporting his wife appropriately. He could not understand her anxiety and was very frustrated that she would not go out. They had stopped communicating and it was evident that their relationship was very strained.

The Dementia Advisor referred to Dementia Support Worker (DSW) who carried out 2 home visits. She identified that the Carers Support Group (CSG) and the Carers Information Programme (CrISP 1) would benefit the client's husband in coming to terms with the diagnosis and understanding Alzheimer's disease.

She felt that this in turn would help him support his wife better. It would also give Mrs R the opportunity to come along and meet other people with dementia whilst being supported by trained support staff.
Mr R came to the CSG for the first time without his wife and engaged well within the group. He reported that his wife did not want to come and was at home with a friend who was visiting. He seemed very happy to meet with the other carers and to have a couple of hours without having to worry about his wife.

Mr R then took up a place on the local CrISP 1 course therefore not attending the CSG for a couple of months. On his return to the CSG Mr R was full of praise for the course and explained how he had really benefited from it. He felt that he understood dementia much better and had much more insight into how his wife was feeling. He had learnt strategies for communicating and coping when he felt frustrated. He reported that communication with his wife had improved and that she was even attempting short bus journeys with him.

He invited the DSW to visit the home again to see his wife and how much things had improved. The DSW carried out a home visit and could indeed see a great improvement in Mrs R's mood and the relationship between the couple.

Mr R has continued to come to the CSG regularly and is a very active, well liked member of the group.

2.7 **The Carers Information and Support Programmes (CrISP)** is an information programme for carers, family members or friends of a person with dementia. It aims to improve the knowledge, skills and understanding of people caring for a person with dementia, by providing effective support and up-to-date and relevant information. The

programme is split into two parts: CrISP 1 and CrISP 2. Each programme is delivered to small groups of up to 12 people.

2.7.1 CrISP1 - is designed primarily for carers of those with a recent diagnosis of a dementia. It covers the following topics:
- Understanding dementia
- Legal and money matters
- Providing support and carer
- Coping day-to-day
- Next steps

2.7.2 CrISP 2 – is aimed at carers of people who have been living with dementia for some time. It covers the following topics:
- Understanding how dementia progresses
- Living with change as dementia progresses
- Living well as dementia progresses, including occupation and activities.

2.7.3 So far across West Sussex there have been 12 programmes delivered to a total of 128 carers that attended the courses. The CrISP courses were delivered in Worthing, Horsham, Chichester, East Grinstead, Bognor, Crawley, Haywards Heath and Billingshurst.

2.7.4 Here a few of the comments received from the evaluation forms:-
- Presented in a way that was not too complex to understand
- Enlightened me about how dementia affects a person in different ways
- Information and coping strategies were very helpful
- Emphasised that the person with dementia is still a person!
- Felt able to ask questions
- Could be made available to the general public so that everybody will know more about dementia

2.8 The impact of MAS

2.8.1 Introducing memory assessment services to West Sussex has had a large impact on the health and social care landscape. MAS has created –

- An increase in GP referral rates. The easy referral route to MAS means that GPs can refer as soon as they have concerns about a patient. There is also a QOF target which supports this.
- Earlier and timelier diagnosis. This early support should lead in future to a delay in customers needing high levels of social care support and residential placement.
- A higher public profile of dementia and early intervention. Third sector partners have been promoting the service and the work to build dementia forums will carry on the work of normalising dementia and reducing stigma
- The above is all extremely positive, however the availability of early diagnosis will mean that more people will be accessing support, both statutory and non-statutory and this will place further pressure on resources.
- A key impact of MAS is that it has highlighted a difference in the levels of service experienced by people who have been diagnosed by the

service, and those diagnosed prior to MAS being implemented. People going through the MAS process will have ongoing support by a dementia adviser or dementia support worker, whereas people diagnosed prior to MAS have less ongoing support. In response, in Crawley, Horsham and Mid Sussex, Admiral Nurses are being recruited to work with the 'pre MAS' patient cohort – this is due to a successful funding application to the 'dementia friendly communities' initiative arrangements in the Coastal CCG area are different with a number of third sector organisations providing advice and support, such as the Alzheimers Society, Chichester and Bognor MIND and the Carers Support Service. Dementia forums and alliances (described in section 5) will further help to bring together support locally.

2.9 Adults' Services

2.9.1 Over the last year, Adults' Services has provided social care support to approximately 2000 people who have had a diagnosis of dementia, with approximately 1,100 receiving care and support at home and 900 receiving long term residential care. People with dementia are supported through a number of different approaches. Following a cost benchmarking exercise, to support the setting of usual maximum rates (ie the weekly amount paid by the County Council for a placement into a care home or care home with nursing), it was clearly evidenced that the rate paid for specialist dementia care should increase. The rate is payable from April 2013 and equates to an 8.4% increase on the rate paid for 2013/14. Given the specialist nature of providing dementia services and to incentivise the development of further quality provision within the market it was considered appropriate to allow additional profit within the usual market rate. To support the development of quality services in this area a specification for dementia services in care homes is being developed with representative providers which sets out clear expectations about the outcomes, based upon the NICE quality standards for supporting people to live well with dementia.

2.9.2 A personalisation strategy is also in development which will articulate the vision, direction and outcomes to be achieved through personalisation, which aligns with the Care Bill, promotes real choice and control, but is affordable now and in the future. A key focus of this will be how to personalise services for those that lack mental capacity to make their own decisions around their care and support, with an emphasis on advocacy. Members will be more fully briefed on this strategy in October.

2.9.3 Commissioners for integrated adult care are reviewing Domiciliary care with the intention of producing recommendations for a cabinet member decision in October. This will take into account the requirement to support independent living, including for those with dementia. By learning from other local authorities and taking an integrated approach to health and social care, the review will respond to the future requirements of directly commissioned services, whilst also ensuring a robust market for people purchasing through direct payments or funding their own care.

3. Future commissioning plans

3.1 Integration

3.1.1 The 2013 NICE quality standards for dementia states that *"People with dementia (should be) enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing"*

3.1.2 Only 5% of people living with dementia have no other co-morbid physical or mental health conditions, therefore the care of people with dementia should be delivered by teams who work together using an integrated approach to the whole person. Customers feedback states that it can be confusing and inconvenient to be visited by a range of professionals and to have to tell the story of their health and social care to each practitioner.

3.1.3 The Directorate for Health and Social Care Commissioning and CCGs, working closely with Adults' Services, have the development of integrated pathways as one of their key commissioning outcomes, particularly for older people. Dementia teams are a central part of this work.

3.1.4 The dementia crisis team will become part of the integrated urgent care pathway, and are currently developing pathways with One Call, RAIT and the admission avoidance teams. This will ease access for GPs and allow joint assessment and care planning.

3.1.5 The care home in-reach team will work in partnership with physical healthcare teams, proactive care and community pharmacy teams to provide an integrated response to care home residents.

3.1.6 Dementia services will also be a key part of the proactive care framework, ensuring a range of support for the most vulnerable customers.

4. The dementia strategy

4.1 A new dementia strategy for West Sussex is currently being researched and written. The strategy will be underpinned by a needs assessment, led by Public Health, and will be developed in partnership with people living with dementia and stakeholders delivering services across West Sussex.

4.2 The strategy will give commissioners a clear vision of the priorities, challenges and where the commissioning focus needs to lie over the next five years.
The work will be complete by February 2014.

5. Dementia friendly communities and forums

5.1 Enabling West Sussex to become dementia friendly is a key priority for commissioners. There is a large cohort of people across the county who are living with mild to moderate dementia and who may not be eligible for statutory services such as social care support. The carers of these people may be struggling with the burden of care or becoming socially isolated.

They may benefit from peer support and a network of local professionals who can help them access services. Dementia friendly communities are vital to increase the level of support for this cohort of people. There is a strong dementia alliance in Crawley, who have accessed funds from the Prime Minister's Challenge in order to expand their work.

5.2 There are also several dementia forums operating across West Sussex. The most well-developed of these is the Chichester & Bognor forum, who have representation from people living with dementia, statutory services, third sector and community groups with an interest in dementia.

5.3 The Alzheimers Society has been commissioned to provide a forum co-ordinator, who will work to set up and initially lead at least a dozen forums across West Sussex. The outcomes of these forums will follow the Chichester & Bognor model to –

- Promote and enable partnership working between all local agencies with an interest in dementia, to avoid duplication of services and build a strong network in each local area
- Map local services in order to provide the best up-to-date information on support available to people living with dementia. People living with dementia often report that the health and social care landscape is confusing and difficult to navigate. Forums will be able to provide clarity on services to people living with dementia.
- Be outward facing .Use every opportunity (community events, local media) to promote dementia awareness, support available and the work of the forums.
- Have people living with dementia at their centre. The forums will be led by the third sector, but will rely on the steer of people with an experience of dementia. This can be people living with dementia, current or past carers. The forums will ensure that their meetings and events are accessible for people living with dementia and that their views shape the work and the direction of the forums.
- Work to identify funding streams outside of statutory services in order to fill service gaps. For example, the Chichester & Bognor forums are currently working to provide activities afternoons and outings to local places of interest for a small charge to people living with dementia and their carers.
- Work towards becoming a recognised dementia alliance. This is a process validated by the Alzheimer's Society that each forum will be given the opportunity to undertake.

5.4 The forum co-ordinator is currently being recruited and it is anticipated that forums will be implemented across West Sussex in this financial year.

5. Carers Support

6.1 Many of the services described above have specific services for carers, for example –

- CRISP programmes, carers support groups, individual assessments and therapies for carers within MAS.

- Carers groups arranged by the Poynings Unit (shared care ward) and carers given the opportunity to participate in group work and social events on the ward
- Dementia crisis team will respond to a carer crisis as well as a patient crisis. SPFT's 'think carer' programme is being embedded across the organisation's dementia services. Carers are supported to undertake a self-assessment of the impact of caring, and are then offered appropriate interventions such as information, signposting and tailored psychological interventions including group therapies.

6.2 However, commissioners acknowledge that carers support extends beyond medical and social care services, and the wellbeing of carers is reliant on them feeling supported for the "other 23 hours" – i.e. when they are not in contact with statutory services.

6.3 Carers support services (CSS) West Sussex tell commissioners that *"support for carers needs to include a range of support groups and local places for carers to go in their community to socialise. These opportunities need to allow carers to express their own needs and views. Keeping the focus on developing dementia friendly communities will help normalise dementia and the dementia carer role so that understanding and support is locally available"*. Carers Support West Sussex (CSWS) offers specific support for Dementia Wellbeing, targeted at carers supporting people with memory loss whether or not diagnosed. Early signposting and referral to CSWS is important so that these carers and others can be offered the full range of information, short breaks funding, links to social networks of support and other opportunities such as low level counselling as early as possible.

6.4 The dementia forums and alliances will be key in making the support described by CSS a reality. Stronger support networks, opportunities for organisations and people living with dementia to work together on improving services, as well as peer support and local action should make a real difference to carers. This work will be monitored and evaluated as the forums and alliances become operational.

6. Reviewing current services

7.1 In line with the development of the dementia strategy, two large service reviews will be undertaken; the dementia crisis team and the memory assessment service. The reviews will look at the investment in the services, the resource versus the demand, feedback from stakeholders, particularly people living with dementia, how the services fit in with the health and social care integration agenda and how these services can continue to be improved and developed - The reviews will take place between August and November 13.

7. Challenges

8.1 There are a number of challenges facing dementia commissioning over the next few years:

- **Demand** - the population of people over 65 is growing, and with that the prevalence of dementia will increase. Early diagnosis will increase demand for services. Equally, there is a steady rise in people under 65 being diagnosed with dementia, which will affect the services commissioned in future.
- **The financial climate** – Commissioners are working in a time of austerity, which in the face of increasing demand for services will present a challenge.
- **Expectation** – Customers are more aware of dementia through public engagement schemes such as Age With Confidence. Although greater knowledge of services and dementia as a whole is positive, it does mean that services will have to respond accordingly. The challenge to commissioners will be to ensure that the third sector is geared up to support those who do not require statutory services, but who need support in the community. The dementia forums will be a key part in supporting this work.
- **Stigma** – dementia still carries a stigma, and it is vital that this stigma is broken in order to reach people who may not come forward for support at present. Forums will work with hard to reach communities and publicise and normalise dementia over the next few years.

8. The future

8.1 Supporting people living with dementia requires on-going engagement from all levels of the health and social care landscape. To ensure success, commissioners need -

- The continued support and scrutiny of HASC
- The high profile of dementia commissioning in the County Council and the local NHS to be maintained and built upon.
- Support from other work streams in order to achieve integration for customers.

8.2 Commissioners would ask that HASC continue to support, scrutinise and endorse the work they are currently undertaking and the plans they have to improve services for customers across the county.

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Background papers - None