

Report to: **East Sussex Health Overview and Scrutiny Committee (HOSC)**

Date: **21 March 2013**

By: **Assistant Chief Executive**

Title of report: **Dementia Strategy**

Purpose of report: **To consider progress in implementing the East Sussex Dementia Programme.**

RECOMMENDATIONS

HOSC is recommended to:

- 1. Consider and comment on progress with improving support for people with dementia and their carers in East Sussex.**
 - 2. Request a further progress report in September 2014, to include an assessment of the outcomes of Memory Assessment Services pilots.**
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1. Background

1.1 Given the older and ageing profile of the East Sussex population, older people's mental health services have been included as a priority within HOSC's work programme for several years. Since the publication of the first national dementia strategy by the Department of Health in February 2009, reports to HOSC have focused on the local response to this strategy.

1.2 The last formal report to HOSC was in September 2011. The Committee noted the importance of improving rates of early diagnosis to enable appropriate support to be put in place which would help people with dementia and their carers to manage living with the disease as effectively as possible. As a result, early diagnosis was a local priority for commissioners and a new, primary care led model for Memory Assessment Services was in development at that time. Significant work was underway to engage GPs in the development of this service, which represented an innovative approach.

2. Dementia service redesign

2.1 In September 2011 HOSC also noted that one proposed aspect of service redesign was to make alternative provision for people currently receiving social care type services through NHS mental health day services. The intention was to disinvest in these services in order to release funds to invest in new models of care, which included Memory Assessment Services, Dementia Advisors, Dementia Carers' Breaks and Dementia Support Services.

2.2 HOSC requested that the Committee's Mental Health Task Group, comprising Cllrs Simmons, Heaps, Pragnell and Rogers (Chairman), consider this proposed approach to service redesign in detail on behalf of the Committee. The Task Group scrutinised the proposals at a meeting in November 2011 and agreed to support the approach being taken which, in the Task Group's view, would enable a better use of resources and the ability to provide a service to considerably more people. The Task Group also noted the arrangements in place to support those current users of the NHS day services who would require a review of their needs and transfer to alternative social care or NHS provision as appropriate. The Task Group Chairman reported the Group's conclusions verbally to HOSC in November 2011.

2.3 In March 2012 a progress report on the implementation of these changes was circulated to HOSC. This confirmed that the decommissioning of NHS day services was proceeding as planned, enabling the ongoing funding and expansion of the Dementia Advisors and Dementia Carers Breaks services. A decision had been made to run 18 month pilots of new Memory Assessment Services, with the intention that these would begin in October 2012. A procurement exercise to commission Dementia Support Services had been unsuccessful, but work was underway with potential providers to develop a partnership approach which would enable the delivery of the services in East Sussex.

3. Progress update

3.1 An update on progress with the East Sussex Dementia Programme, supplied by the joint NHS/Adult Social Care commissioners, is attached at appendix 1 for HOSC's consideration.

3.2 Martin Packwood, Head of Joint Commissioning (Mental Health) and Nigel Blake-Hussey, Joint Commissioning Manager (Older People's Mental Health) from NHS Sussex/Clinical Commissioning Groups/ESCC Adult Social Care, and Elisa Vaughan, Sussex Area Manager for the Alzheimer's Society, will attend HOSC to discuss the report. The Alzheimer's Society is the local provider of the Dementia Advisor service.

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Draft Report to: HOSC
Report Title: Progress with East Sussex Dementia Services Redesign
Report Authors: Martin Packwood/Nigel Blake-Hussey
Report Date: 21st March 2013

Recommendation: The HOSC is asked to note the report and, subject to any further analysis/information required, continue to support the East Sussex Dementia programme.

1. Context

The publication of the National Dementia Strategy, *Living Well with Dementia: A National Dementia Strategy (DH, 2009)* and its update, *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy (DH, 2010)* have placed an unprecedented focus on the need to improve the quality and quantity of services, to enable people with dementia to receive formal diagnosis of the illness earlier, and to support both them and their carers to live well as the disease progresses.

The improvement of services for older people in general is a key priority for East Sussex, as projections show that the local population, which is already older than that of most other areas nationally, is likely to continue to age. Dementia is therefore a key area of concern. The number of older people with dementia is projected to increase by 10 percent from 9,833 in 2010 to 10,816 by 2015 and by 24 percent to 13,930 by 2020.

However, in line with other parts of the country, only approximately one third of people predicted to have dementia in East Sussex have a formal diagnosis, with the result that early access to treatment and support services is compromised, and presentations often occur late in the progression of the illness and / or in crisis.

Capacity for dementia diagnosis and support has not been sufficient to encourage and address underlying needs being met and, whilst national expectations and local aspirations are high, meeting these needs has been set against a backdrop of unparalleled financial and organisational challenge.

Despite these challenges, NHS Sussex, Clinical Commissioning Groups (CCGs) and East Sussex County Council, working together, have undertaken a comprehensive re-design of services to significantly increase their quality and quantity.

This report aims to provide an update on the accomplishments from dementia services redesign and seeks to secure HOSC support for its continuation.

The report will focus on the following areas:-

- Memory Assessment Services
- Other dementia services developments
- Service redesign imperatives & achievements

2. Memory Assessment Services (MAS)

An early formal diagnosis for people with dementia is a key priority both nationally and in East Sussex. The key to addressing this objective locally has been the recent commissioning of new Memory Assessment Services (MAS) which increase capacity to accept referrals from GPs, whose patients and / or their carers suspect they may be developing memory problems that might be the early signs of dementia.

Following an extensive development process involving the active involvement of GP advisors / Clinical Commissioners, a model for Memory Assessment Services was agreed in early 2012. This would provide for high volume, very focused diagnostic services, with associated prescribing and care management planning on discharge.

A critical part of these services was also to be accompanied expansions in Dementia Advisor services, which, provided by the Alzheimer's Society, provide post-diagnostic information, advice and support for patient and families, *throughout* the course of the illness – a further separate briefing providing more information is attached at annex 1.

New MAS launched at the beginning of October 2012 and their capacity has been commissioned at levels sufficient for diagnostic rates to reach national target levels of 70% over the next 3-5 years. This should form a cornerstone to many other dementia service developments that will depend for their efficiency and effectiveness upon the illness having been identified in advance and, hence, able to be communicated across whole health and social care systems as people come in to contact with them.

What is also innovative about new MAS services in East Sussex is that they are being provided by a number of different organisations, using slightly different approaches, as part of an 18 month pilot. This will be evaluated against quantitative and qualitative measures, including patient and GP satisfaction with them, in order to assess which is best.

In addition to provision by our local NHS Trust and by an incoming new private sector organisation (MAC Healthcare Ltd), MAS services in one area (Hastings and Rother) are being provided by a consortium of GPs who have taken up a post-graduate training course in dementia care and treatment, which is the first of its kind in the country - indeed it was created to serve this purpose by East Sussex commissioners, and hence would not have existed otherwise (places are now being taken up by candidates from other areas of the country).

Reporting from the 1st period of MAS activity, October 2012 – December 2012, has been now been reviewed by commissioners, who are confident that levels of referrals being received are more than sufficient to meet desired diagnostic rates. It would appear that national and local campaigns over Christmas and the new year, targeting those “worried about your memory”, have proved successful in breaking down stigma associated with dementia, and encouraged more people to come forward for a diagnosis.

Finally, and in recognition of some of the innovative aspects of dementia services development in East Sussex, the Regional Dementia Centre at Canterbury/Christchurch University has expressed interest in working with us to develop and publish an academic review and evidence base for the local service.

HOSC will be kept informed as required as the MAS pilot progresses.

3. Other Dementia Services Development

Commissioners recognise that as increasing numbers of older people are diagnosed with dementia, there will be commensurate increases in needs for more support services. Expansions in Dementia Advisor services will be critical to this, but others will also have an important contribution to make and hence form part of the East Sussex Dementia Programme.

3.1 Carers Respite Breaks

The provision of respite breaks for carers of people with dementia is critical to the well-being of both the patient and their carer, helping maintain and support continuation of the caring role and an avoidance of crisis and carer breakdown. Like the provision of Dementia Advisors, carer respite breaks initially began in East Sussex as a nationally funded demonstrator site pilot in 2010/11, and funding was continued jointly between Adult Social Care and PCTs in 2011/12. The service has been continued in 2012/13 and now forms a substantive element of dementia support in the county.

Provided by East Sussex County Council Adult Social Care it involves both home-sitting and group activity being provided either in a planned way and / or on a short-notice basis. To date the service has provided approximately 38,000 carer respite breaks of this sort.

3.2 Dementia Support Services

As the incidence of dementia increases with old age, so also do other physical illnesses and dependencies that any of a range of services will be appropriate to meeting, including day services and residential care. The aim of support services is to contribute specialist dementia care knowledge, experience and expertise, to older people in whatever setting they may find themselves.

3.2.1 Activities & In-reach

Older people living with dementia in the community may attend local community clubs or other social facilities, or statutory day services, or live in care homes, none of which may have particular resources available to help staff identify and help support those whose particular needs arise from their having dementia, potentially alongside a range of complex needs which are having to be met.

The provision of activities and in-reach programmes which deliver reminiscence therapies, cognitive and memory stimulation, have been commissioned from a partnership formed between the Alzheimer's Society and Sussex Partnership NHS Foundation Trust.

Significant work was undertaken to broker this delivery model and a start date for the new service is now planned as 1st April 2013. This service will deliver up to 75 x eight week memory management and cognitive stimulation courses per annum across the county, with the potential to engage with up to 900 people with dementia each year wherever they may congregate and be able to benefit.

3.2.2 Care Home In-reach

It is also recognised that many older people with dementia may already be living in care homes, whether this was recognised on their admission or developed over time, and hence may benefit from varying degrees of specialist knowledge and understanding by staff of how best to manage and care for them, and in particular with sensitivity to their needs as they arise from their dementia.

Significant numbers of older people living in care homes, who by definition have often the most complex and severe range of needs, are admitted to acute hospitals each year.

A number of inter-agency health and social care initiatives are being taken to ensure that where such admissions are avoidable they are avoided, and that services are in place to either provide an alternative or to prevent deterioration in conditions that might otherwise mean admission is unavoidable – for example, where symptoms are unable to be accurately and reliably recognised by staff due to their being ‘masked’ by dementia.

A specialist dementia Care Home In-reach service has also been commissioned in East Sussex where it has been in place for over 18 months. It includes specialist dementia nursing staff, input from psychiatrists and (from 2013) occupational therapists. Its aims are to help care home staff to recognise dementia and improve the sensitivity and hence quality of care they provide to people with this illness, as well as to reduce the frequency of behavioural and clinical problems arising, with which they may be otherwise unable to cope – triggering an avoidable admission.

Funding for these services has been extended, for initially 6 months into 2013/14, whilst a Development Programme is pursued, aimed at significantly increasing overall prevention and effectiveness through greater integration with other (non-dementia specialist) services being provided to care homes.

4. Service Redesign Imperatives & Achievements

It will hopefully be recognised by HOSC that a great deal has been achieved in the development of dementia services since it was last provided with an update in March 2012.

The ongoing support of HOSC to this programme is, and will continue to be critical since, in the context of unprecedented financial challenges, achieving the improvements in services described above often requires that other, existing services are reduced, revised or removed from what is currently available, in order to make way for (and indeed to fund) what is new.

Although such service redesign is therefore an imperative, and a difficult one to achieve, it is nonetheless possible to do.

It is therefore also hoped that HOSC will be reassured that bringing about the service developments described above has been achieved through a process of service redesign that has been sensitively and well managed, with minimal adverse impact both on individuals affected and on the overall balance of available services.

In this context, HOSC may recall that it was previously briefed about a comprehensive review of NHS provided day hospital activities for older people with mental health problems which indicated that, for dementia patients, it was largely social care and carer respite needs that were being met. This was being taken up by relatively few people attending on average for just one morning or afternoon session per week, whilst overall funding levels for these services were costing some £1.8m per annum.

By closing these NHS provided day services from April 2012 it has been possible to release sufficient funds to implement all of the services described above.

Of equal and critical importance in achieving this transformation was the partnership working between the NHS and Adult Social Care services which enabled every existing user of NHS day

services to be identified well in advance of planned closures, have their needs assessed and alternative provision made for them, including directed access to day centres, respite breaks for carers, and support from Dementia Advisors.

For those older people attending NHS day hospitals with functional rather than organic (dementia-related) mental health problems, released funds were re-invested to ensure that relevant programmes continued to be provided by the Trust for their needs in other settings.

5. Inter-Organisational Activity

Whilst a great deal has been achieved in the recent period, the scale of dementia prevalence in an increasingly aging population in East Sussex does mean that maintaining the momentum of resource-releasing service redesign, and re-investment in transforming services, will require an ever greater reach across from specialist mental health services and into all parts of the health and social care economy, where older people with dementia appear and services are obliged to respond.

We know that not every part of the health and social care system is currently well able at all times to respond to the particular needs of older people with dementia and, as a result, care and treatment can be less than optimal, of a poorer quality than desired, and result in costs being incurred unnecessarily, for example as a result of avoidable acute hospital admissions.

For these reasons, the next stages of the East Sussex Dementia Programme are focusing increasingly on inter-organisations working – ensuring an effective contribution is made by specialist dementia services to mainstream programmes, such as for more proactive management of Long Term Conditions, through multidisciplinary working.

HOSC may wish to request further reports and updates on this work in due course.

6. Conclusion

Since previously reporting to HOSC, significant work has been undertaken and completed to improve the range and quality of dementia services in East Sussex.

The benefits to East Sussex residents are now starting to be seen.

Commissioners will continue to develop and pursue the Dementia Programme, working alongside colleagues in new Clinical Commissioning Groups, and in the context of the Council's Health and Wellbeing Strategy.

HOSC is asked to note this report and, subject to any further analysis / information required, continue to support the development of the East Sussex Dementia Programme.

The Dementia Adviser Service

The Dementia Adviser Service has been designed to ensure that people with dementia get the most out of life by guiding them to all the information they need not only about the illness, but also where to find the most appropriate services in the local area. The service provides reliable information tailored to the individual's needs, so that people with dementia can make decisions that are right for them. Every person referred to the service is given a named Dementia Adviser and if in need of additional support, a named Dementia Adviser volunteer. The named contact remains constant (except when change is inevitable, eg staff turnover) providing an information and signposting service throughout the person's life with dementia and offers additional information to immediate family members.

Case Study – Dementia Adviser, Lewes and Havens

Mr R was referred by the Consultant Psychiatrist from the Newhaven Memory Assessment Clinic. Mr R lives alone in his own home and was diagnosed with dementia with Lewy Bodies.

The DA contacted him a day after receiving the referral and explained her role to him and arranged an appointment to visit. He stated that he was not receiving any support and did not understand what his diagnosis meant. He did not know if he was receiving Attendance Allowance (AA).

The DA visited him 12 days after receiving the referral. Mr R's home was very untidy and dirty and he had paperwork (bills, bank statements, etc) covering every surface. Most of the paperwork was dated 5 or more years old. He had a large dog at the property that he stated was his only companion and was worried his dog would be taken from him if he couldn't walk him. Due to his cataracts he told the DA that he could not work his phone correctly and apologised for cutting her off (although he had not done so). His car was parked outside but he stated he was frightened to use it.

The DA discussed with him how he was coping on a daily basis and he informed her that he could not read his letters, suffered from hallucinations and was constantly needing the toilet. He stated he was able to feed himself and take care of his dog and home. He informed her that his biggest worry was that the Council were sending bailiffs to reclaim his Council Tax (CT) debt (caused by overpayment of CT benefit, a debt of over £3,000). He informed her that his son had tried to sort out the debt but that he did not have time to assist his father as he had his own young family and was just starting his own business.

The DA visited him three times and during these visits arranged the following:-
Met with Mr R's son to explain to him and Mr R what the symptoms of his diagnosis were and how to cope with them.

Liaised with Dept of Work and Pensions to confirm that he was receiving AA.

Liaised with the District Council to send him the CT exemption certificate. Suggested to Mr

R's son that once the exemption was in place to negotiate a reasonable amount for his father to pay regularly until the debt was paid off.

Encouraged Mr R to see his GP to discuss his urinary problem, the hallucinations and to have the CT exemption certificate signed.

Discussed with Mr R and his son that he must inform the DVLA of his diagnosis and they would decide if he could continue to drive but not to do so until he had heard from them.

Discussed with Mr R that he needed to have his papers in order so they did not contribute to his confusion.

Assisted him to liaise with the hospital to find out when his cataract operation would be. Explained to him how he could get help at home through a Community Care Assessment (CCA).

Informed him of assistance through the RNIB of suitable telephone handsets.

Informed him of a voluntary organisation who could help him walk his dog.

Gave his son Alzheimer's Society factsheets regarding all the above topics to go through with his father so they could both understand more and have the information to refer to at any time.

At the last visit by the DA, Mr R knew he was on the waiting list for his cataract operation. He had been exempted from paying CT and his son had negotiated an affordable regular payment for the debt.

He and his son had sorted out all his paperwork and put it into a filing system.

Mr R stated he would be contacting the RNIB and the dog charity for assistance.

He had received anti-biotics from the GP for the urinary infection and would discuss his hallucinations with the Psychiatrist at his next visit to the Memory Clinic.

He had contacted the DVLA and was waiting to hear from them.

He had declined a Community Care Assessment as he did not wish to have carers in his home.

The DA confirmed that he and his son had her contact details should they wish to discuss further concerns and she will contact Mr R again in the future if she does not hear from him to review how he is coping.