

Minutes

DEMENTIA SERVICES TASK & FINISH GROUP

**MINUTES OF THE DEMENTIA SERVICES TASK & FINISH GROUP HELD ON FRIDAY 26
NOVEMBER 2010, IN MEZZANINE ROOM 1, COUNTY HALL, AYLESBURY, COMMENCING
AT 10.00 AM AND CONCLUDING AT 12.10 PM.**

MEMBERS PRESENT

Mr M Appleyard, Mrs M Aston (C), Mrs W Mallen, Ms J Puddefoot and Mrs L Rowlands
(Aylesbury Vale District Council)

OFFICERS PRESENT

Mrs J Burke and Mrs E Wheaton

1 APOLOGIES FOR ABSENCE AND CHANGES IN MEMBERSHIP

Apologies were received from Mr Trevor Egleton and Mrs Avril Davies.

2 DECLARATIONS OF INTEREST

There were no declarations of interest.

3 MINUTES

The minutes of meeting held on 9 November 2010 were agreed as a correct record.

4 SERVICES IN THE COMMUNITY

The Chairman introduced Frances Finucane, Community Mental Health Team (CMHT) Manager, Julie Dale, Social Care Team Leader and Helen Stradling, Community Psychiatric Nurse. The Chairman also welcomed Brian Gilbert who is a member of LINK.

Frances, Julie and Helen started by taking part in a role play to demonstrate how two people (George and Alice), who were both suffering from dementia, had very different experiences.

Frances concluded the case study by saying that people's circumstances are different and each step of the dementia pathway has to be flexible enough to accommodate the point at which the person comes into contact with services. She went on to say that the following areas would be covered in their presentation today:



INVESTOR IN PEOPLE



- The Referral process to memory services and the Community Mental Health Team
- The Benefits of Early Diagnosis
- The Barriers to Early Diagnosis
- Social Care and Support.

The Referral process to memory services and the Community Mental Health Team

Frances explained that the memory services are part of the Day Hospital provision in each of the localities.

Further information on Memory Clinics and CMHT is attached.

During discussion, the following main points were made and questions asked.

- “George” took the initiative to make an appointment with his GP as a result of family concerns. The medication he was given meant that he could be in control of his treatment and he could stay at home and look after himself. A Member said that “George” relies heavily on his family for their help and support and expressed concern that in today’s society, many families are fragmented. The Member asked whether any improvements have been made to reduce the number of crisis points which are reached where sufferers have to be brought home by the police as they are found wandering the streets. Julie added that neighbours also support dementia sufferers – especially in rural areas. A Member asked whether neighbours are put off helping out sufferers and whether enough is being done to support local communities.
- A Member commented that dementia sufferers can become institutionalised very quickly in Care Homes and can deteriorate at a faster rate than if they are left in their own homes. Mr Gilbert commented that people can be well looked after at home if you can get an early diagnosis.
- Frances said that there is a need for greater awareness both at national and local level and she mentioned that the main aim of the Dementia Action Alliance (www.dementiaaction.org.uk) is to raise the awareness of dementia and to drive it forward.
- All referrals come to the CMHT and the team works very closely with day hospitals. There is an open referral system but most referrals come from GPs. The team rely heavily on the information provided by GPs – including very thorough medical history, results of blood tests (to identify diabetes, kidney infection and other possible medical conditions). GPs know what information is needed by the CMHT and they work within the national framework and the NICE guidance and they know what the triggers for referral are.
- A Member asked what the difference is between Alzheimers and dementia. Helen explained that dementia is a very broad term used to describe the condition – Alzheimers, vascular dementia and Lewy body dementia (similar symptoms to Parkinsons disease) are all different types of dementia. She said that sometimes patients display signs of Parkinsons first which then advance to memory problems.
- It is important to try and diagnose Alzheimers first and the drugs currently available slow down the affects.
- A Member asked whether there are many specialist homes across the County. Julie responded by saying that there are specialist care homes across the County and patients are provided with a pack detailing which care homes specialise in which medical areas.
- A Member felt that it was not always necessary to provide all the information at one time and wondered whether it would be more beneficial to have less information which was perhaps more relevant to a dementia patient.

- A Member went on to say that not all Care Home have trained professionals to handle dementia patients and felt that they take people in but are unable to care for them effectively. Julie explained that the CMHT supports care homes and care homes are regulated by the Care Quality Commission who operate a star rating.
- A Member asked whether care homes receive extra funding if they look after patients with dementia. Julie explained that the CMHT can apply for additional care if required.

Frances took Members through the process after referral. Patients attend a Memory Clinic once they have been referred by their GP (they should receive an appointment within 4 weeks of the referral). Patients then undergo a screening process called MMSE (Mini Mental State Examination). If the patient scores between 13 and 20, they are eligible for medication. If they score over 20, then they can receive medication privately. Those who score over 20 are then assessed again after 6 months to review progress and they can get support. If necessary, they can be referred back to their GP.

Community Psychiatric Nurses (CPN) carry out assessments in people's homes and they can provide support in patients homes thereafter. CPNs provide professional support between the patient and other service providers.

Frances went on to explain that the same consultants work across the same hospitals so there is some level of continuity. Cromwell Ward at Stoke Mandeville Hospital is a County-wide ward. In Amersham, there is the Haleacre unit and in Wycombe, there is a day care centre called Shrublands.

Mr Gilbert provided Members with his experience of dealing with a family member who was diagnosed with dementia and he spoke specifically about the transition from home to a care home which he said can be very traumatic. He said it can be very difficult to ascertain what level of service care homes are going to offer. He felt that it was very important to have 3 stages in the process – residential to nursing to EMI but this requires a large complex with the space to build the different levels of care. Mr Gilbert felt that the doctor visits were infrequent in his experience.

Frances went on to say that a lot of the referrals that her team receive are from staff members who work in the care homes.

- A Member asked whether there are currently vacancies for consultants in care for older people. Frances responded that there are vacancies on the in-patient side at present but she said that there is not a huge turnover in the Communities team.
- A Member asked how many people work in the Communities team. Frances said there are 25 people based in Aylesbury which includes administrative staff and there are similar numbers of staff in the other areas.
- Helen explained that patients have to be seen by their GP at the outset before they are assessed by the CMHT as there could be physical reasons which need to be highlighted by a GP.

The benefits of early diagnosis

Helen took Members through the benefits of early diagnosis of dementia.

- It enables people to make informed choices and decisions about treatment and the future whilst they still have capacity.
- It allows them to take advantage of the use of anti-dementia medication, other medication trials and other research studies whilst they might still be effective.

- It allows families and carers the opportunity to enjoy the time with the person before their capacity and abilities diminish.
- It enables family and carer's time to be prepared and make important decisions, practical and legal arrangements with the person before their capacity diminishes.
- It enables the person to maintain and enjoy independence for longer by adjusting or adapting their life style whilst they still have capacity and functional abilities e.g. exercise, diet, leisure, hobbies and social interaction.
- It enables the person to implement memory strategies and adjust their lifestyle in order to maximise independence in all aspects of their life before their functional and cognitive abilities diminish.

Helen then went on to outline some of the barriers to getting an early diagnosis.

- No single service has the responsibility to make the early diagnosis of dementia - services must work in harmony to make early diagnosis possible.
- Not everyone has family, carers or close friends who will back and encourage them to seek help if a problem with memory is beginning to start.
- Not everyone is able or wants to recognise that they have a memory problem which they might be able to get some help and advice about.
- Many people remain physically quite well and never have cause to visit the GP which is the usual place where memory problems begin to get picked up.
- There is no national screening programme for dementia.
- There is still a stigma around mental illness generally including dementia - so many people and their families keep it quiet.
- There is still ignorance about dementia amongst the general public. There needs to be much more national and local awareness raising and education about the issues across all areas of society and all age groups.
- There is still a lack of awareness among some statutory organisations like the police, fire service and ambulance service - all people who may help with early recognition.
- There is still a tendency to medicalise memory problems in the early stages - awareness campaigns could provide quick memory tests and signposting for the general public at stands in shopping centres or GP surgeries, for example.

During discussion, Members asked the following questions and the following key points were made.

- How do you ensure independence for longer as people are more likely to go to their GPs for diagnosis if the benefits of early diagnosis are made very clear. The Member felt that simple headline facts might encourage more people to go to their GP to discuss their symptoms. Julie explained that the information has to be tailored for each person as their needs will be different to other patients.
- A Member commented that people are not as aware of dementia as other diseases.
- It is important to make sure the Care Plan is thorough and that it is completed in conjunction with the patient's family. Future planning is very important and costs of a care home can be very expensive.
- A Member asked about funding and what the rules are for who is eligible for Local Authority funding. Julie explained that there is continuing care funding and care can be funded via a combination of local authority funding and private, family funding.
- Julie explained that if they feel a patient is at risk, then they would place them in a Care Home and work with the family. The team offers welfare benefit advice.
- How often does the team visit patients and what services does your team offer to dementia patients? Helen explained that it very much depends on what the patient wants – some patients they see once a week, some they see once a month as every

patient is different and their needs are different. Some patients require social services support more than others.

- Frances said that the team aims to keep patients out of the wards so they will sometimes provide intense support at home. If the team has to visit patients more than twice a week, then it has probably reached crisis point. She explained that they work with people who have other mental problems such as depression and anxiety, they are not just working with dementia problems.
- Do you work with other services, for example, the police? Julie said that the team works closely with the PCSO's.
- A Member felt that the barriers to early diagnosis outlined above can be bridged when opportunities are discussed and that the benefits of early diagnosis need to be effectively articulated so that people understand. Frances agreed and mentioned the need to raise the awareness in schools and within the voluntary sector. The Dementia Alliance is working hard at a national level to raise the awareness and the whole system needs to work together. She stressed that a cultural change in society needs to happen.
- Families need to have more open discussions about dementia before it happens. This should be encouraged.
- Frances provided an example of a recent event where Dr Murray asked a room of 50 people who had a lasting Power of Attorney. Not very many people put their hand up. She said that this is a very easy thing to do and people should be encouraged to do this.
- A Member acknowledged that we live in a very different world now and there can be tensions between the patient and their family.
- A Member asked who applies for continuing care funding and how is it triggered? Julie explained that the Care Home can trigger it or the family can request a continuing care assessment to be carried out at any point. She went on to say that the screening assessment provides an initial indication as to whether a fuller assessment is then required.
- If a family persuades a patient to go into a Care Home, can the Care Home then intervene and say that a patient should be cared for in their own home? Do Care Homes take a commercial view or do they take advice from Social Services? Julie responded by saying that the person's best interests would be central to any decisions made.
- Is there a requirement on Care Homes to call in services, especially when the funding is running low? Julie explained that there is no requirement if they are self-funding.
- A Member asked whether patients are given an estimate of costs when they look into Care Homes – based on averages. Julie explained that it is very difficult to do this and precise figures can't be given. Mr Gilbert went on to say that this is why early recognition is so important so that staying at home for as long as possible is the better option.
- A Member felt that dementia awareness should be taught at school as part of the PSHE curriculum. Another Member felt that teaching it in schools would be meaningless to many people unless they were actually faced with someone who was suffering with dementia.
- Is there capacity in the system to deal with a greater demand from people who are diagnosed early? Frances explained that many people suffer with memory problems and the system would not be able to cope with an open referral process.
- A lot of GP surgeries run well-woman and well-man clinics. Could they test young people at the same time? Frances said that there are currently no national dementia screening programmes.
- Flu-clinics would also be a good place to promote dementia and the services on offer to people.

- A Member asked whether it would be possible to find out whether patients are asked questions about their memory when they attend certain clinics.

Social Care and Support

Julie took Members through the services which are available to patients and their families once diagnosis has been confirmed.

- Early diagnosis should help the person and family make choices about the support and care they need whilst they still have the ability to decide what they would like and what would help them.
- Early diagnosis will help the professionals get a much better understanding of the person, what their life story is and how the care, support, services and advice can be individualised to their individual needs.
- Our aim would be to try and help the person remain in their own home and live in their own community for as long as it is possible, feasible and safe for them to do so.
- Support for families and carers is essential from the start to ensure they get the right advice and information about services, legal and financial matters but also to get an understanding of how things might progress in the future.
- Hearing the views of people who have experienced dementia before or families who have had to cope with dementia is an important part of helping others come to terms with the condition and the impact it has on lives e.g. support group, moving on groups.
- Self directed support and personalised budgets should help people and their families make more flexible arrangements and choices for their own care.
- The use of Telecare and assistive technology does enable many people to remain more independent and live within their own home for longer. Simple memory aids, clocks, calendars and pill boxes through to door sensory and tracking devices.

During discussion, Members asked the following questions.

- What respite is available for carers? Julie explained that the carers grant is decreasing. Currently carers receive one week of respite a year. Mr Gilbert went on to say that respite is very important for both the patient and the carer. He gave an example of a Care Home where respite for carers is provided on the same site with inter-connecting wings. Respite also provides an opportunity to see how patients respond to being in a Care Home environment.
- Do you work with Crossroads? Julie said that they do sign-post people to this organisation.
- A Member commented that we tend to use more drugs these days and was any research being done to see why this may be so. Frances said that a lot of research points more towards lifestyle and medical issues such as obesity, diabetes, blood pressure and alcohol are the main triggers.
- Is dementia heredity? Frances said that by 2019, 50% of 90 year old women will have dementia.
- The after-effects of a stroke can disguise the symptoms of dementia.
- It isn't just older people who can suffer from dementia – young people can also get it. Binge drinking may well lead to more young people suffering from dementia in the future.

The Chairman thanked Frances, Helen and Julie for their very informative presentation and discussion.

The next meeting will take place on Friday 14 January at 10.15am in Mezz Room 2, County Hall, Aylesbury.

6 FORMAL MEETING ENDS

7 VISIT TO A CARE HOME

CHAIRMAN

Memory Clinic or CMHT?

The memory services are part of the Day Hospital provision in each of the localities. The service in Aylesbury is well established and provides a programme of screening, assessment, prescription of Cholinesterase Inhibitors, (ChEI the dementia medication), follow up and signposting

All referrals to the CMHT and the memory services are generally, but not exclusively, from the persons GP. All referrals come into the CMHT as the gate keepers in the first instance. An MDT decides if the individual patient should be seen under the memory services or the CMHT. The professionals are reliant on the GP providing enough information to make that decision and clinical judgement

As part of the National Service Framework (NSF) for older people and the guidance from the National Institute and Clinical Excellence (NICE) there are protocols in place that enable the local GPs to know when they should trigger a referral to the specialist mental health services. Of course the GPs are reliant on the patient and or their family/carer presenting at the surgery with a problem in the first instance.

The factors that would influence whether the patient is seen by the memory services or the CMHT depends at what stage their condition appears to be at and what type of dementia (if any) they might be suffering from. The memory service is best placed to assess and treat people, as appropriate, in the earlier stages of their memory problems. If the clinical picture is leaning towards Alzheimer's disease then the structured assessment, prescription of ChEI, diagnosis and review provided by the memory clinic is going to be more appropriate and beneficial. Typically these people may still be functioning quite well at home, some driving and engaging in a range of leisure activities. Many are living with their spouse or family who have noticed specific issues with the person's memory or ability to carry out tasks. The GPs referral may indicate some significant changes in the patient's clinical presentation.

For patients seen in the memory service, they and their family/carer are offered an initial appointment in clinic within four weeks of the referral. At that appointment various screening assessments will be carried out including an assessment for the carer as appropriate. One of the assessments carried out is the Mini Mental State Examination (MMSE) which is the critical score indicated by the NICE guidance for the prescription of ChEI. Patients are then offered a further appointment with the Psychiatrist, who is able to give the diagnosis. If the diagnosis is indicating an Alzheimer's type dementia then the patient may be eligible for a ChEI as long as their MMSE score is in line with NICE guidance. These people will receive regular follow up in the memory service and support with their diagnosis. All patients/families assessed in the memory service will receive information about memory problems, strategies for coping and signposting on to other helpful resources.

For those scoring above 20 on the MMSE (not meeting NICE guidance for ChEI) they will be offered a review by the memory service at six months to

assess for changes or deterioration and may be offered treatment or discharged as appropriate. At any point these people can contact the service again for support and or get re referred by their GP. The memory service can also at any point refer on any patient to the CMHT if it looks likely that the situation with regards to the patient's condition or circumstances at home have become more advanced or complicated.

If the initial GP referral indicates a more complex picture with a more advanced memory problem, perhaps much less functional ability, issues with behaviour or social functioning, little social support at home, more physical frailty and a clinical picture conducive with a vascular dementia, then it is likely that assessment, treatment and support at home by the CMHT is going to be more appropriate. Many of these patients could not get to a clinic.

For patients to be assessed in the community by the CMHT, they will receive a similar assessment process of their mental health needs, memory and social circumstances. This will usually take place within a week or two of the referral. They will be allocated a specialist professional to coordinate their care within the service and at the interface with partner organisations as appropriate. These patients are likely at this stage to require longer term support from the CMHT and other services with regards to care and diagnosis. The same psychiatrists work across the whole service and as necessary will see patients or advise other CMHT staff. They can prescribe ChEI as appropriate for patients seen by the CMHT.