

# Minutes

## *DEMENTIA SERVICES TASK & FINISH GROUP*

**MINUTES OF THE DEMENTIA SERVICES TASK & FINISH GROUP HELD ON TUESDAY 9 NOVEMBER 2010, IN MEZZANINE ROOM 2, COUNTY HALL, AYLESBURY, COMMENCING AT 10.15 AM AND CONCLUDING AT 1.00 PM.**

### **MEMBERS PRESENT**

Mr M Appleyard, Mrs M Aston (Chairman), Mrs A Davies, Mr T Egleton, Mrs W Mallen and Ms J Puddefoot

### **1 APOLOGIES AND CHANGES IN MEMBERSHIP**

Apologies were received from Mrs Lindsay Rowlands. There were no changes in membership.

### **2 DECLARATIONS OF INTEREST**

There were no declarations of interest.

### **3 INTRODUCTION OF THE REVIEW**

Margaret Aston, Chairman of the Dementia Services Task and Finish Group, welcomed everyone and explained that the purpose of the Task and Finish Group is to look into dementia services countywide. The review is due to finish early next year and she explained that by the end of it, Members will have spoken to as many people as possible. Mrs Aston went on to say that Dementia is a very topical issue and has already started to generate a lot of public interest. She said that she had been involved in a radio interview on the subject earlier that day following a press release sent out by the Communications team.

### **4 THE BENEFITS OF EARLY DIAGNOSIS AND SERVICES AVAILABLE - VIEWS FROM THE VOLUNTARY AND COMMUNITY SECTOR**

The Chairman introduced Ken Dorling, Locality Manager, Berks, Bucks & Oxon from the Alzheimer's Society. Mr Dorling started by saying that the Alzheimer's Society was formed 31 years ago and there were over 250 branches across the UK at that time which gave rise to disparity and created a postcode lottery regarding access to services. The Trustees decided to create 49 localities in the UK with the aim of having more services in more places and the



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new structure came into effect on 1 April 2010. The main focus for the organisation has moved away from the carer to the person suffering from the condition.

In Buckinghamshire, there are branches in Beaconsfield, Aylesbury and Milton Keynes so they can pool their resources. There are 6 part-time staff across the North and South of the County and Mr Dorling explained that he can move staff from Milton Keynes as well so it provides a greater level of flexibility within the organisation.

Mr Dorling explained that there are a number of services running across the County and he mentioned the "Bee-Friending" scheme which has been running for around 18 months. It is run by trained volunteers (currently 30) and acts like a "buddy system" and people with dementia are teamed-up with people of a similar profile in order to get the best match possible. This service provides 100 hours of client contact per month and also allows for respite for the carer. It has proved to be very valuable. Mr Dorling said that he hoped to add another 15 volunteers to the service this year and the volunteers receive very intensive training across 5 sessions.

Mr Dorling went on to say that another valuable service which the organisation provides is "Singing for the Brain" which provides an opportunity for carers and people with dementia to enjoy time together in a safe environment. He said that around 70 people currently attend the weekly sessions in Beaconsfield. The sessions run for 5 weeks and then there is a 2 week break. Mr Dorling read out a couple of very positive testimonies from people who have attended the sessions. These are attached for information.

The sessions are part funded by a prevention grant and the balance is raised through voluntary fund raising. Mr Dorling explained that it isn't just about signing, it is a structured activity. He went on to say that there are people who attended the sessions at various stages of the condition. A member of staff has to attend the sessions as part of the health and safety requirements.

[Mike Appleyard arrived at 10.35am]

Mr Dorling told Members about Memory Cafes which are specially designed for people suffering with dementia. He explained that the sessions are designed to be very inclusive and can help carers and sufferers by providing information on legal issues, the benefits available to them as well as presentations on Health & Safety and Fire prevention issues. He said that these have been very successful to date and he is looking at the gaps across the County to see whether more cafes can be developed. He highlighted Chesham as an obvious gap.

Mr Dorling gave Members the following overview of the Alzheimer's Society and the services it provides:

- There are over 700 branches of the Alzheimer Society nationally. They are the best source of information and they deal with any aspect of dementia and related issues.
- Talking Point - an online support and discussion forum, for anyone affected by dementia to ask for advice, share information, join in discussions and - most of all - feel supported. The forum is managed by the Alzheimer's Society and is supported by a dedicated team of volunteer moderators. Talking Point is available 24 hours a day, 365 days a year and can be accessed worldwide by anyone with a computer and internet access
- The Local and National Dementia Helpline can provide information, support, guidance and signposting to other appropriate organisations.
- 'Living with Dementia' magazine is produced monthly and features news, case studies, expert tips and advice for carers and people with dementia
- Home visits - the most valuable service but the most expensive (travel costs and staff time)
- News letters to carers and professionals covering topical issues and fund raising events
- Carer support groups

- Former Carer support groups and life coaching events giving advice on employment opportunities such as volunteering etc

After the presentation, Members asked the following questions and raised the following issues.

**Many people receive early diagnosis of dementia but, unfortunately, nothing further happens. If this is the case, what is the point of early diagnosis and is this statistically supported.**

Mr Dorling advised Members these are not statistics; it is what people have told the Alzheimer's Society. He added that there have also been situations where GP's have told patients to come back when their symptoms worsen.

**What is being done to help relatives who are not carers, to interact with family members with the condition who are in care homes?**

Mr Dorling explained that there is a lot of information available or which can be provided. Annual courses for carers are held in the County which address how to interact with a person with the condition. If relatives are made aware of what to expect then they can deal with situations which may arise. More effective treatments are emerging as time passes. There is the need to understand the condition and to adjust and prepare for the future in an appropriate way e.g. legal & financial issues.

**Setting aside lobbying and the role of society, where would you place the Alzheimer's Society services available in Buckinghamshire on a scale of 1 to 10 (10 being full vision/mission), and what is needed to make progress.**

Mr Dorling told Members that services are developing over time and he would currently rate the Society as a 6 or 7.

The vision for Buckinghamshire is to have:

- Core services in every conurbation
- A link from rural locations to these services
- A dementia support worker to assist every GP surgery.

Mr Dorling advised Members that the Department of Health is currently running a pilot scheme around Dementia Advisors and Peer Support and that a bid made for Bucks Peer Support reached the last stage but unfortunately was not successful. He added that HealthBridge has been evaluating groups and although the role of a Dementia Advisor is considered to be good, unfortunately it is too expensive. It is, therefore, a good idea to take advantage of the services already being provided and to expand on these.

**How could early intervention and diagnosis be improved?**

Mr Dorling said improving public and professional awareness and the understanding of dementia is the first of seventeen recommendations in the National Dementia Strategy which was published in 2009. There has also been a campaign entitled 'Worried about your Memory' and several television advertisements to try and raise awareness.

**There is concern about GP awareness of the condition and the response given to people. We need to make sure that GPs are adequately trained to recognise symptoms.**

Mr Dorling advised good quality early diagnosis is also one of the recommendations in the National Dementia Strategy. Diagnosing the condition can be very difficult as symptoms might be similar to those indicating depression. Lots of GPs are willing to admit more training is needed.

Ms Whiteley from Carers Bucks added that it would be better if GPs were willing to listen and engage with family members and carers and take their opinion into account.

**GPs are expected to give expert advice. There is a concern that there seems to be an inability to refer patients for a more accurate diagnosis.**

Jane Taptiklis, Assistant Director, Commissioning, NHS Buckinghamshire explained to Members that a Scoping Paper had been taken to GPs for discussion. In response, GPs said that the condition was difficult to diagnose, they felt uncomfortable giving a diagnosis if there were no services to signpost people to and they were keen to see a good choice of signpost options.

Mr Dorling added that early diagnosis gives the opportunity for health management i.e. drug/non drug intervention. Some drugs have been shown to slow down decline in the condition. The idea of non drug intervention is to adjust the home environment accordingly and create a routine which gives positive benefit to those with the condition as well as family members.

**There are a lot of groups and a wealth of expertise out there. How much does the Alzheimers Society tap into what is available or do they work in isolation?**

The Alzheimers Society works together with groups such as Carers Bucks, Crossroads, Age UK and Mind and signposts people to activities i.e. walking groups.

**Are there services other than the Alzheimers Society which people can be signposted to (e.g. speech therapists) and what is the role of psychologists who work with GPs on other issues in the County?**

Jane Taptiklis advised Members that in response to the Dementia Strategy, the Primary Care Trust (PCT) had advised that lots of money was being spent around the condition but unfortunately in the wrong place. Jane added that the PCT have funded a Scoping Project looking at what they are doing now, what they should be doing and how to get there and although there are some areas of excellence, these areas are fragmented. The PCT are currently looking at the value of early intervention and diagnosis, evidence based treatments (a literature review has subsequently been requested) and care homes. A picture of what the PCT are working towards should be known in approximately 2 to 3 months time.

**What timescales are the Primary Care Trust (PCT) working to?**

Jane Taptiklis advised Members that dementia is a big issue for Buckinghamshire and given the profile of the County there will be an increase in needs. Jane added that a 'quick fix' is not possible and the PCT and the County Council need a long term plan in place.

**In the future there may be a GP consortium rather than the PCT. What is being done to involve the existing GP consortium to ensure continuity and that work will not have to start again in future?**

Ojalae Jenkins, Service Development Manager, Adults & Family Wellbeing advised Members that an implementation plan has been created against each Dementia Strategy recommendation and that key partners are in place to take responsibility for each objective in the strategy. Ojalae added that the first plan will be available in January and that the Strategic Group will meet every three months to monitor its progress.

**There is concern about people in care homes who are subsequently found to have dementia and staff treating them like 'naughty children' as they have no idea how to deal with the condition. What can the Alzheimer's Society do to help these people?**

Mr Dorling explained that the Care Quality Commission monitor the standard of care and that if requested, the Alzheimer's Society go into care homes to train staff.

The Chairman commented that a care home has to be registered in order to take dementia patients and patients are moved to a registered home if they are subsequently diagnosed with dementia.

A Member added that care homes are private businesses and that there is a long period of time between Care Quality Commission visits.

The Chairman advised Members that the schedule for Care Quality Commission is three visits per year (one announced visit and two unannounced).

**A Member asked Jane Taptiklis what is the priority of the project for the PCT on a scale of 1 to 10, is this being driven forward, and what are the PCT's views on the ownership and management of the scheme as GPs may not be aware of future monitoring and management.**

Jane Taptiklis explained that the issue is rising up the agenda and that the PCT had already put money into the Scoping Project looking at the future of GPs. Jane added that Buckinghamshire are early adapters of GPs becoming Commissioners, which gives a chance to explore what the right model will look like. There needs to be a good action plan in place and for the issue to remain as priority.

The Chairman advised Members that Jane Taptiklis is setting up a meeting with GPs.

**A Member asked what happens to individuals who do not have families and how do Alzheimer's nurses fit into GP surgeries.**

Mr Dorling told Members that there is a whole range of work to be done around this issue i.e. the Black & Ethnic Minority community and those living alone in rural locations. He added that statistics show that the local branch of the Society are only servicing the needs of 5% of people with dementia in Buckinghamshire and that there are 750,000 known dementia sufferers in the County. One of the advantages of early diagnosis is people being able to remain in their own home for longer.

**The Chairman asked if the Alzheimer's Society works in conjunction with Social Services.**

Mr Dorling confirmed that the Alzheimer's Society works in conjunction with Bucks County Council, the Older People's Partnership Board and the Carers Partnership Board but not enough was done which comes down to resources.

The Chairman thanked Mr Dorling for a very interesting presentation.

## **5 LIVING WITH DEMENTIA - A CARER'S PERSONAL PERSPECTIVE**

The Chairman welcomed Mrs Renee Kennedy and explained that Mrs Kennedy would be providing an account of what it is like to care for someone with dementia.

Mrs Kennedy started by explaining that it was about 6 years ago when she first noticed that her husband was acting strangely. He was diagnosed with dementia and they lived with this for a couple of years. Mrs Kennedy said that it was so sad to see him deteriorate so quickly and in the end she could not let him go out on his own. He kept falling over and in the end he was admitted to hospital and put on a geriatric ward where the nurses thought he was just being rude. He spent two months in hospital and at the end of this time, he was unable to walk out of hospital having been able to walk in. Mrs Kennedy felt that it was not appropriate for her husband to have been admitted to hospital and felt that the physiotherapy which he received in hospital could have been administered at home.

Mrs Kennedy said that her husband is now in a very good nursing home in Stone where his care is excellent and the help and support for relatives is excellent. She sits on the Care Home's Committee and feels that there is a "family" atmosphere at the home. She went on to say that music is very important for dementia sufferers. Her husband is now bed ridden but he still recognises her and she keeps a memory box for him with items from his past such as sporting trophies, a tennis ball and a golf ball.

Mrs Kennedy explained that when her husband was first diagnosed, they did not get much help and they had to delve around to find useful information. She mentioned that the Red Cross had been supportive and her husband had attended various activities arranged by them.

During discussion, Members asked the following questions and raised the following issues.

- GP surgeries need to be looked at. A Member said that in his local surgery, a booklet listing all useful organisations was put in the waiting area but when the GP was asked about the booklet, he knew nothing about it. The Member felt that the local organisations had spent a lot of time developing the booklet but the GPs seemed unaware of it.
- Ann Whiteley, from Carers Bucks, explained that it can be difficult to get past the practice manager in some GP surgeries. She felt that if there could be more engagement directly with GPs, it would be better. Ms Whiteley explained that Carers Bucks has a volunteer who goes around to the local surgeries to place the right information in the waiting areas and speaks to the receptionists/practice managers about what is available. She went on to say that the number of GP referrals to Carers Bucks has increased over the years.
- A Member spoke from personal experience and was not convinced that GPs had moved forward in the last 15 years. The Member went on to express concern that dementia is only now being considered a priority by the PCT when they have been aware of an ageing population for a long time.
- A Member felt that some GPs were not very welcoming to older people, especially those who are suffering with dementia. The Member felt that some GPs are not engaging with the population and there appears to be many gaps in the information available for dementia sufferers.
- A Member felt GPs and the PCT need to be more pro-active and the task and finish group provides an opportunity to highlight the gaps.
- Mrs Kennedy mentioned that the care home where her husband is a resident holds a regular surgery at Haddenham Health Centre where people who have concerns about family members, or themselves, can drop-in for help and advice. These need to be well advertised.
- Ms Whiteley explained that Carers Bucks hold regular workshops for collaboratives and she stressed that it is crucial to be involved in the process from the start. She said that there is a need to get areas of work onto GPs agendas so that they are fully briefed about what help is available to sufferers.
- A Member asked whether there is a local GP who is a champion in dementia. Ojalae Jenkins responded by saying that there is a champion who works at the Wendover practice (Dr Liz Fergusson).
- A Member asked Mrs Kennedy whether there was anything which she would have wanted more of at the start of the process when her husband was first diagnosed with dementia. Mrs Kennedy responded by saying that access to information about what the future holds for those who suffer from dementia would have been useful. She said that the current "Bee-Friending" system would have been very useful and more guidance on how to care for her husband would have been useful. She said that the information, help and support which she now receives has improved over the years but this was not great when her husband was first diagnosed six years ago.
- A Member felt that it can come down to resources and trying to balance resources against funds available. Another Member responded by saying that it does not always come down to financial resources, Sometimes it can be about finding someone to talk to who has been through a similar experience.
- A Member felt that there should be a dementia specialist at every GP surgery and felt this should be explored further when Members visit the surgeries as part of the review.

- A Member commented that respite for carers is extremely important but sometimes it can be very expensive for carers.
- GPs need to be made aware of the effect that they have on dementia patients and their carers through not communicating effectively with them.
- Ms Whiteley explained that Bucks Carers has a very good relationship with GPs in the South of the County and they had a Flu Festival recently where around 250 attended and there is the hope that this will become an annual event. Ms Whiteley went on to say that practice managers tend to be the gatekeepers for the GPs so it's important to have a good relationship with them. She suggested using carers as dementia champions and asking them to monitor the literature available in reception areas.
- A Member felt that the GP set-up is changing. PFI funding is being used to build surgeries and GPs are "renting" rooms in buildings and there is a move away from the local doctor of years ago which raises issues around doctor continuity. GPs are developing business models and cited The Practice as an example.

## **6 DATE OF NEXT MEETING**

The next meeting will take place on Friday 26 November at 10am in Mezz Room 1.

**CHAIRMAN**