

MINUTES OF THE GREAT BENTLEY PATIENT PARTICIPATION GROUP MEETING

HELD ON THURSDAY 11 MAY 2016

AT 6.30PM IN THE MITCHELL ROOM, GREAT BENTLEY VILLAGE HALL

Chaired by Melvyn Cox
Present: Charles Brown, Vice Chair/Treasurer
Barry Spake, Communications & Membership Officer
Dr Sean O'Reilly, Partner,
Anne Coupe-Harris - Dementia.org.
And 15 present.

1. Welcome, Introduction

The Chairman welcomed everyone to the meeting, especially our guest speaker Anne Coupe-Harris.

2. Apologies for Absence:

Mr Houghton; Mrs Sitch; Mr & Mrs Ward.

3. Minutes of the last Meeting

Minutes of meeting 21/04/2016 were approved.

4. Guest Speaker Ann Coupe-Harris "Dementia Friends & Family Friendly Communities"

Thank you for inviting me along this evening. It is quite appropriate that I'm here tonight as this is Dementia Awareness week and it's something we do as a society is to go out and talk to various groups. Dementia is becoming more prevalent in our world. We have 850,000 people with Dementia in the UK, and that roughly equates to one person being diagnosed every 3 minutes. The figure is set to rise to a million in 2025. Dementia doesn't just affect older people. Over 40,000 people under the age of 65, one in fourteen over 65, and one in ever 6 by the age 80 will have dementia. This is called early-onset or young-onset dementia. The chance of developing Dementia increases with age. One in 14 people over 65, and one in six people over 80 has dementia. It is more common among women than men. We are based in Clacton and cover the whole of Tendring, and have an office in Colchester, but we have offices all over the country, and, as an organisation, we run over 3,000 support groups at anyone time, including Dementia Support at Memory Clinics; Dementia Cafe; Carer Information and Support Programme; Activity Groups; Singing for the Brain. People with Dementia are able to sing, when unable to remember many things. They have a couple of hours having a sing song every fortnight in Clacton. As part of Dementia awareness week on Tuesday (17 May 2016), people with Dementia, carers and volunteers, from the whole of Essex, took part in singing at Chelmsford Cathedral. As a society we want to let everyone know that they are not alone. It is not just the patient who is experiencing Dementia, but the whole family. Carers Resource Information Support Programme (CRISP): CRISP1 is for people newly diagnosed. CRISP 2 is for people later on in Dementia, In Tendring we have nearly 3,000 people with Dementia, and in Colchester nearly 2,000. We go and visit people at home. So if anyone has concerns they can ring us up and we can help them. We speak to the people at home and confirm if it really is Dementia and not some other problem. You can help people with Dementia by doing small things, like putting signs on cupboard doors to remind them where certain items are stored. We think of memories like a bookcase analogy. If you can imagine that I'm an 80 years old lady and next to me I have a bookcase and that bookcase represents my life: on the top shelf is my most recent memories, like what time I got up; what I had for breakfast etc. and as we go down the bookcase by the time we get down to my waist it would represent my memories when I was 40 and would represent my memories from that time. When I get the diagnoses of my Dementia that would cause my bookcase to rock and the books in my short term memory on the top shelf would fall off because they are the ones most at risk – that's my short time memory. So as my Dementia progresses I'm not going to be able to remember short time memories, but might well be able to remember memories from when I was 40. I can probably tell you what I was doing when I was a child. What we say to people just because they suffer from Dementia they can still have a very good quality of life. Dementia is a progressive disease like any other. It is a progressive disease with no cure. Do you know the difference between Alzheimer and Dementia? Dementia is the umbrella and the different type, including Alzheimer, is one of the many types, as there is actually 100 different types of Dementia. What causes Dementia? Dementia occurs when the brain is damaged by

a disease. There are many known causes of Dementia. The most common is Alzheimer's disease. The first sign is usually short term memory loss. Other types of Dementia include Vascular Dementia; Mixed Dementia (Alzheimer's Disease and Vascular Dementia); Lewy Bodies and Frontotemporal Dementia; and Pick's Disease. Each of these diseases affects the brain in slightly different ways. Dementia is a progressive disease. How quickly this happens varies from person to person, with many people staying independent for years. There is no known cure for Dementia, but there are ways to help with the symptoms and make life easier at each stage. There are medications available that may help with some types of dementia and stop or slow down the symptoms for a while. That's why it is important that you see a doctor as soon as you suspect that there is a problem. There are certain conditions that are hereditary, such as Huntington's Disease, which can go on to cause Dementia; Cadasil, Parkinson's Stage 2, that is also hereditary. For the most part it is not hereditary. It all boils down to how you look after your body now, the better it is prepared for the future. Keeping our brain active, keeping our body active, eating a good healthy diet, hopefully will prepare ourselves for the future.

5. Question and Answers session:

Q. if someone with Dementia speaks about something they think that they have done, which you know that they haven't done, do you contradict them or agree? **A.** It's best to play along to a certain degree. Some carers struggle with this, those who have not been trained try to correct the person and this can cause an argument. **Q.** Do you have trained people in hospitals to deal with Dementia patients? **A.** I'm working very closely with health organisations and am setting up clinics in doctors surgeries and have 12 clinics running at present and it's for anybody and everybody who is registered with that surgery. If they have a concern about their own memory or a loved one's memory they can actually come to see me at the surgery as I do have clinics running for that and we have a weekly presence at Clacton Hospital and Harwich Hospital, and we are about to start to go into Colchester Hospital. Two Dementia trained nurses are there, but we run a two day course the nurses are generally trained and they are not always aware of dementia problems. Sometimes, when at hospital, you have to ask for the Dementia Specialist nurse.

Q. You mentioned the medication that's been tried, but say that there is no cure. **A.** The medicine will not cure Dementia but hopefully will slow it down. There are three drugs that they can use for Alzheimer's but, again, it will not stop it only slow it down. No two people are alike as it depends on what type of Dementia, when it gets diagnosed and the severity of it.

Q. What are the general problems encountered? **A.** Short time memory loss is the most common factor. Not knowing what they've done, where they are. Some people get very depressed and feel very isolated and stop going out as they don't want the problem of meeting somebody in case they have to try to have a conversation with them. If we get Dementia diagnosed early then we can help the whole family. **Q.** How do we get in contact with somebody for help. **A.** I've brought some handouts that contain information on how to contact us. People need to talk to their Doctor as soon as possible as it may well be something other than Dementia. **Q.** My friend's wife is not aware of anything and he is going to need support. **A.** We can go to social services and tell them what we have found, although we may have to go back to the memory service to find out the situation. We would be happy to visit them both and review the situation. **Q.** Is there a quiz for self help?

A. There are several tests that can be carried out. **Q.** It was mentioned in the packaging leaflet that Statins can affect memory? **A.** Dr. O'Reilly stated that it was very uncommon for Statins to affect memory. The patient comes into the surgery, but more often, it is the partner who brings the patient in. What we do is ask questions as there are other causes that affect memory loss, apart from Dementia. Such as profound depression, thyroid problems etc. We then screen and carry out blood tests. There are questionnaires that the GP can use one for the patient, one for the partner, and depending on how you score equates to sometimes normal ageing; sometimes needs referral so we would then refer the patient to a memory clinic where they would normally have a brain scan and then they would see a specialist who would ask more questions.

A short discussion followed concerning poor memory.

Q. How is Dementia awareness week progressing. **A.** It is going very well as we have events on every day this week.

Q. What is the best way to handle a situation when a relation forgets things, and doesn't want to admit it? **A.** If you keep a diary of events it will help you when you contact your doctor to arrange help for them. Dr O'Reilly stated that most patients come into the surgery for tests and check-ups and we can ask a few questions if the doctor has been made aware of the problem they are able to take it further. **Q.** Is the Dementia service available 7 days a week. **A.** We do have a national helpline and our office at Clacton is open Monday to Friday inclusive.

Note: Clacton Office (Tendring Area) 01255 474650 tendring@alzheimers.org.uk
National Dementia helpline 0300 222 1122

6. Refreshment Break:

Courtesy of Alan and Judy Bishop.

7. Surgery News Dr Sean O'Reilly:

Not much to report but the good news is that we are getting another Doctor, Dr Katy Daniels who will start in July. More staff will be available at the surgery as we are in the process of advertising which should make things more easier. Beth McLean - GP Registrar (Trainee GP) is currently under training with Dr O'Reilly to cover Phlebotomy services. Periodically the staff (Doctors, Senior Staff etc.) hold a meeting on a Saturday to discuss patient care. We do get quite a few inappropriate demands e.g. have had a sore throat for a few hours and want to see a doctor right away. If anyone has any ideas on the matter please let the surgery know. This can be very annoying. We allow 10 minutes per patient which is not enough.

8. Any Other Business:

Q. Have you had the results of the CQC Inspection? **A.** No. They said six weeks and it is now eight weeks.

New Horizon Travel Ltd run a bus from Frinton-on-Sea to Colchester General Hospital, via Great Bentley, and we need to start a petition to organize this. Melvyn Cox to obtain further details.

A vote of thanks for Judy and Alan Bishop for providing refreshments. £10.00 was collected which was handed to Melvyn Cox to be entered into the PPG funds.

9. Next Meeting:

Our Next meeting will take place on Thursday 16 June 2016 at 18:30 hours in the Mitchell Room

The meeting concluded at 19:30 hours.

Charles C. Brown.

(In Secretary's absence.)