

CITY OF LONDON PENSIONERS ASSOCIATION
WELFARE CONFERENCE 5TH OCTOBER 2016

Presentations and discussions

Editor's Note: This pamphlet might be loosely said to contain the proceedings of the 2016 Welfare Conference.

The 2016 Conference had two presentations/speakers. Following the conference, the speakers wrote articles reflecting the content of their presentations.

This booklet is a (nearly) verbatim reproduction of the transcript on a presentation on dementia. The presenter speaks from personal and campaigning experience on recognising dementia, managing it in a loved one, and dementia medication, as well as ventures she is or has been involved in or initiated. These include Dementia Clubs and the Virtual Dementia Tour. This article starts on the next page.

DEALING WITH DEMENTIA as a Carer, Councillor and Campaigner

Speaker: Councillor Lisa Rutter, Brunswick Park Ward, London Borough of Barnet

Good Morning everyone,

I am delighted to be speaking to you here today at the Pensioners' Association conference about 'Dealing with Dementia'. I would like to start however by saying a little about myself. I was born in North London and went to teacher training at Middlesex University to study English and Art. I remember when I was deciding about my career my parents telling me at the time - you have 3 choices; you can be a doctor, a solicitor or a teacher. I decided to go for teacher but it wasn't long after when I decided that it was not for me. I worked for many years in banking, and that's when I also met my husband Mark and we have a son we are very proud of. After 10 years in banking I decided to follow a path in litigation. I worked for the Insurance Ombudsman Bureau and then finally with Coutts Bank as a Special Matters and Fraud Manager dealing with very high profile cases. I was also however always very interested in politics and joined with my husband our local constituency association so that we could express our views. In 2006 I then decided to go into Politics and was elected Brunswick Park Ward Councillor for the London Borough of Barnet. I sit on various committees, I chair a residents' forum and I am also a governor for 2 schools.

In May 2010 I became Deputy Mayor of the London Borough of Barnet and in May 2011/2012 I was elected the Mayor of the London Borough of Barnet. It was a great honour. As Mayor I was able to see and learn so much about the various communities in the Borough and tried to promote their good work through the local press. I am the Borough's Ageing Well Champion and I also now work for the Care Quality Commission. I became a Freeman of the City Of London in September 2011, a Liveryman of the Pattenmakers in July 2013 and became a Court Assistant of the Guild of Freemen of the City of London in October 2013.

Why am I interested in dementia?

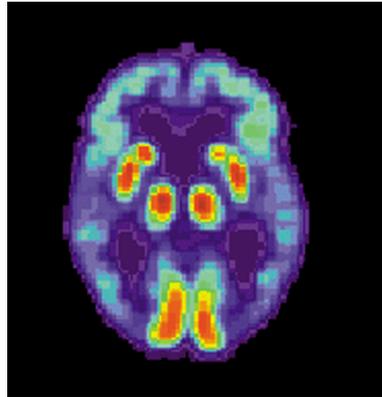
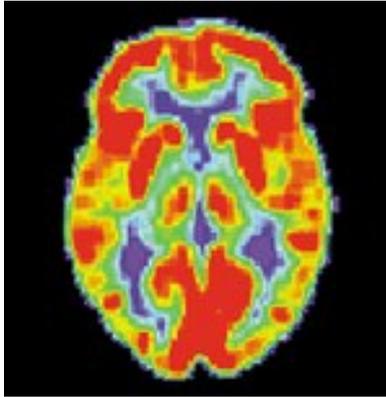
When I became Mayor of The London Borough of Barnet I raised money for 3 charities; The Alzheimer's Society, Barnet Young Carers & Siblings and The Outward Bound Trust. I still maintain contact with all the charities as they mean a great deal to me.

I chose the Alzheimer's Society however because in 2010 this is when my mother was first diagnosed with Alzheimers. I had no idea what it meant at the time but I knew that this was a charity I needed to support. With the money I raised for the Alzheimer's Society I funded and opened the first Alzheimer's Society Dementia Café at the Finchley Memorial Hospital in the Borough of Barnet in August 2013.

So what is dementia?

It is said to be the most feared illness. There is no evidence to show that it can be inherited and it is not related to natural ageing.

Dementia is an umbrella term. It describes the symptoms that occur when the brain is affected by certain diseases or conditions. Some of the symptoms include loss of memory, mood changes and problems with communication and reasoning. There are many different types of dementia although some are far more common than others. It describes a loss of mental ability (cognitive impairment) that is expected with ageing. It's enough to affect day to day activities and gets progressively worse.



We have 100 billion nerve cells (neurons) that make every aspect of our being. This PET scan demonstrates how Alzheimer's affects brain activity.

The left image shows a normal brain while the right image is from a person with Alzheimer's and has a lot of blue and black areas, which indicates reduced brain activity

resulting from the disease. By the time you die with dementia, the brain has lost 10% of its weight which, as Christopher Eccleston said in his recent campaign, is about the weight of an orange. Dementia is a disease which attacks the brain piece by piece until it strips away everything that makes you - you. It's the cruellest disease as your family watches you deteriorating. The person that they used to know slowly vanishes and all they are left with is just the body.

With an increased population and as people are living longer, dementia has become a growing concern and is now the greatest health concern for people over the age of 50. It can even appear at a younger age, when it is called early onset dementia.

The number of people in the UK with dementia is expected to rise from 850,000 in 2016 to just over two million by 2051. This will have an impact on the quality of life for those with dementia and on their families and carers.

80% of people living in care homes have a form of dementia or severe memory problems. Two thirds of people with dementia live in the community while one third live in a care home.

David Cameron said in a speech in 2014 – “the truth is that dementia now stands alongside cancer as one of the greatest enemies of humanity” In a report in 2016, Dame Gill Morgan – Chair of NHS Providers said that “Studies show that dementia is now the most feared disease, it is more feared than cancer. People fear Alzheimer's and other forms of dementia more than cancer – yet dementia research receives only a tenth of the funding.”

Types of dementia

I will now talk about 4 main types of dementia;

The most common type of dementia is Alzheimer's disease, but scientists have been unable to reach consensus about the cause of the condition, and despite more than 400 drug trials, nothing has been shown to combat the disease until now. There has recently been a new breakthrough drug which I will talk about later (see page 13). Alzheimer's symptoms include memory loss and difficulties with thinking, problem-solving or language, but every person with Alzheimer's does not necessarily experience the same symptoms in the same way. In addition some people will also have hallucinations.

Vascular dementia is the second most common cause of dementia and can occur when blood flow to the brain becomes reduced. It can be developed after a stroke. In many cases these problems are linked to underlying health conditions, such as high blood pressure and diabetes, as well as lifestyle factors such as smoking and being overweight.

The third most common cause of dementia is Lewy bodies, which is caused by deposits of an abnormal protein called Lewy bodies inside brain cells. These deposits are found in people with Parkinson's disease. People might experience hallucinations and Parkinson's type symptoms. This disease often progresses more rapidly than Alzheimer's.

Frontotemporal dementia - (also known as Pick's disease).

This is relatively rare form of dementia, which affects the frontal and temporal lobes of the brain (the front and sides) in particular. These parts of the brain are largely responsible for language and the ability to plan and organise and important in controlling behaviour. It often starts at a younger age.

There are many other rarer diseases that may lead to dementia. For example, some people with Multiple Sclerosis, Motor Neurone disease, Parkinson's disease and Huntington's disease may also develop dementia.

Medication

I will now talk about the main drugs, which are available for dementia;

Aricept which is used to treat mild to moderate dementia caused by Alzheimer's disease.

Exelon which is used for Alzheimer's and Parkinson's

Reminyl which is used to treat the symptoms of mild to moderate severe dementia.

Namenda, which is now available as **Memantine**, is licensed for the treatment of moderate-to-severe Alzheimer's disease. In people in the middle and later stages of the disease, it can slow

down the progression of symptoms, including disorientation and difficulties carrying out daily activities. There is some evidence that Memantine may also help with symptoms such as delusions, aggression and agitation.

Whilst the above medications are available for dementia, they are not a cure.

If medication is provided early, when dementia is first diagnosed, it can delay the disease progressing but there is no guarantee how these medications will work on each person and for how long. As the dementia progresses, the medications need to be adjusted or changed. It's trial and error.

With my mother, medication for dementia did not work. The only medication which worked for my mother was called – Mirtazapine. This medication is an antidepressant – i.e. a mood enhancer - which also stimulates appetite. I learnt about this medication through speaking to another carer whose mother had not been coping well with the dementia medication. She was always sleeping; she had no interest to do anything until she tried Mirtazapine. I saw how she was before and how this worked on her after and changed her to a new woman. It was amazing. It is not the answer for everyone but for my mother this was great. It provided a calming effect, making her happy and also controlled anxiety and confusion.

Mental capacity

How do we know when someone has lost mental capacity?

People with dementia often become unable to make some decisions for themselves as their condition progresses. When this happens, the person is said to 'lack capacity' The Mental Capacity Act is the law in England and Wales that protects and supports these people, and outlines who can and should make decisions on their behalf. It covers important decision making relating to an individual's property, financial affairs and health and social care. It also applies to everyday decisions, such as personal care, what to wear and what to eat.

I have recently discovered however in a case that I am dealing with for one of my carers, how the Mental Capacity Act can be very problematic and challenging if all the paperwork is not properly in place in advance. If there is any confusion, which then raises questions, everything can go horribly wrong.

Before any individual is admitted in a care home, it is so important for them to be properly assessed, and for this assessment to be documented. Based on this assessment the care home will then decide whether that individual is suitable to be admitted.

When choosing a care home, your choice should not only be based on how convenient it is to get to and how wonderful the care home looks, you should also check on the Care Quality Commission website to see what ratings the care home has received after an inspection. If the care home is not rated 'Good' in all areas then you should perhaps consider choosing another care home.

A family member dealing with dementia is one challenge but when that person you love goes to a care home, the challenge of dealing with dementia is no longer in your hands but in the hands of the care home. You rely on the fact that they are fully trained and they understand how to deal with individuals with dementia.

You put the trust in that care home to provide the best care for your loved one. However, as a care home has to look after many individuals, it is impossible to have the tailored care for each individual.

Dealing with dementia is not easy as every day is a new challenge to face

As a Carer myself I had no idea what to expect and learnt the hard way. From what I have seen and learnt over the years looking after my mother, I believe that Dementia is the worst disease that anyone can have.

When my mother was diagnosed with dementia, I was suddenly provided with lots of reading materials that were useful but not enough.

Unless you experience caring for someone with dementia, you would not have a true understanding. There are no simple instructions to prepare you and there is no 'one glove fits all'. Nothing really prepares you for what lies ahead.

When I became Mayor in 2011, my mother's Alzheimer's was still in its early stages. She attended my Mayor making ceremony but she did not understand what the occasion was about. I remember her saying to someone, 'this is my daughter's wedding.'

Every person with dementia is different but the most common symptoms with Alzheimer's are that you cannot remember the things you did one minute ago, one hour ago or 2 days ago. The only memories are old memories. If I take my mother out and she has a lovely time, when I take her back home she would have forgotten where she was.

We took her on holiday once – we travelled by plane but she had no idea she was on a plane even though the flight was long and tiring. Don't we all wish that we could sometimes forget long travels like that!! Although amusing – it is also sad.

We learnt after this holiday that it is not a good idea to take someone with dementia away from their familiar surroundings. It was very hard for us throughout the holiday as we had to calm her most of the times when she became agitated. People with dementia just want familiar surroundings and regular routines.

There are some good days but most days are difficult. You notice little changes daily as the dementia progresses. You have to be patient and understanding. Most of all when dealing with dementia is to remember that the person with dementia will be saying things to you that may not make any sense. They could also mention a family member that you know is already deceased but to their mind they are still alive. You as the carer need to go along with it. You must not correct them for example and tell them that the person they are referring to is dead as this would be very

distressing to them. It doesn't matter how many times you correct them they will not remember. It would be cruel to keep correcting them.

For my mother, it has got to the stage now that her husband is, in her mind, her daddy, as she believes she is a young girl. Sometimes when she sees my father walking, because my father limps a little because of the arthritis in his knee, she says 'Who is that old man that can't walk properly?'

She makes us laugh sometimes with some of the things she says and my father tries to see the funny side too but I can see the hurt in his eyes. She calls me by my name but unfortunately I am not her daughter, I am either her mother or her sister. She always listens to me and feels comforted as she trusts me. My father however has a hard time with his wife. They say that whatever your character was before you had dementia, it develops and becomes stronger. For example, my mother was always the boss in their marriage and even though she now has dementia, she still manages to boss my father and tell him off.

We as the carers have to understand that the dementia sufferer is living in their mind in another world. They not only see things differently but their comprehension of their surroundings is different. If we disturb that world, we are causing them more pain. We therefore need to try and understand them by their actions and their expressions, and when they do say something, to try and understand what they are trying to say.

How many of us here are carers or who know someone who is caring for someone with dementia?

If you have an illness and your mind is ok, you can come to terms with it.

However if you have Dementia you are not able to understand what is wrong with you and therefore have to rely on someone to care for you and make decisions for you. You don't want to be a burden to your children and you want to keep your dignity, but this can be very difficult as the disease progresses.

Someone with dementia can unfortunately progress to the point when they are unable to eat because they forget how to swallow and then they need to go into nursing care.

How many of us here forget where we put something?

I suspect many of us here forget. We go upstairs to get something but by the time we reach the top of the stairs we have forgotten what we went upstairs for. We all forget but then we quickly remember again. Imagine if you didn't remember.

For someone who has just been diagnosed with Dementia they are suddenly in another world and unless there is someone that cares and understands, this person will be left feeling isolated and frightened.

Has anyone seen the film “Still Alice”?

Alice is played by Julianne Moore who won an Oscar for best actress in Still Alice. It shows when Alice is diagnosed with Alzheimer’s disease, what happens to her and how her family react. It is very sad but uplifting and gives you some understanding of dementia.

If you are worried about your memory or about someone else, the first step is to make an appointment to see the GP who will first rule out other conditions that may have similar symptoms to dementia that may be treatable, for example depression, vitamin and thyroid deficiencies, brain tumours or any other infections.

The GP will then do a Cognitive Impairment test.

If after the test the GP feels further investigation is required, you will be referred to the Memory Assessment Service. You may also be referred for a head scan and also to have some blood tests.

Here are 6 examples of questions you can be asked in a test.

Six-item Cognitive Impairment Test

1. What year is it?
2. What month is it?
3. Try to remember this address
John Smith, 42 High St, Bedford
4. About what time is it (within one hour)
5. Count backwards from 20-1
6. Say the months of the year in reverse

I will be asking you at the end of my presentation if you remember the address in this test.

I will now talk about the 10 early signs of Alzheimer’s. It is estimated that 400,000 people have dementia but do not know they have it. An early diagnosis therefore can help with early treatment, preparing and planning for the future.

10 Early Signs of Alzheimer’s

1. Memory loss

Do you easily forget information you just learned? Do you lose track of important dates, names, and events? Do you ask for the same information over and over? Do you rely heavily on memory aids like Post-it notes or reminders on your smartphone?

2. Trouble planning and problem solving

Do you have trouble making plans and sticking to them? Is it tricky to follow a recipe, even one you've used many times? Is it hard to concentrate on detailed tasks, especially if they involve numbers? For example, can you keep track of your bills and balance your cheque book?

3. Daily tasks are a challenge

Even familiar things can become hard. Do you have trouble driving to a location you go to often? Can you complete an ordinary task at work? Do you forget the rules of your favorite game?

4. Times and places are confusing

Can you fully grasp something that's not happening right now? Are you disorientated? Do you get lost easily? Do you forget where you are? Do you remember how you got there?

5. Changes in vision

Is it harder to read the words on the page? Do you have trouble judging distance? Can you tell colours apart? This is important because it can affect your driving.

6. Words and conversations are frustrating

Vocabulary becomes harder. Can you find the right word you're looking for? Or do you call things by the wrong name?

7. You lose things

Everyone misplaces things from time to time, but can you retrace your steps to find them again? Do you put things in unusual places, like your watch in the refrigerator? Do you accuse people of taking things?

8. Lapse in judgement

Have you made poor decisions lately? Do you make mistakes with money, like giving it away when you normally wouldn't? Are you showering as often? Do you take less care of yourself? Do you dress for the wrong weather?

9. Social withdrawal

Are you scaling back on projects at work? Are you less involved with your favourite hobbies? Do you lack motivation? Do you find yourself watching television or sleeping more than usual?

10. Mood changes

Do you get upset more easily? Do you feel depressed, scared, or anxious? Are you suspicious of people?

Your dreams after retiring

Everyone's dream after working hard in their lifetime is to retire and enjoy their remaining years doing all the things they planned on doing.

My father's love of his life has been taken away from him. This is not what he pictured in the latter part of his life. His dream was to retire in Cyprus with his wife.

In fact they did go to Cyprus to retire and for about 2 years they were enjoying their time but suddenly something happened to my mother. We used to send my mother DVDs of Coronation Street and other soaps she enjoyed watching when she was in England, and then suddenly she was no longer interested.

We had no idea that this was the beginning of dementia. My father was finding his wife doing strange things. He had no idea what was wrong but we all thought it was just age related. As time went on however my father was concerned and at times finding it difficult to talk to his wife. He needed help and therefore sadly their retirement in Cyprus ended and they came back to England.

What has dealing with dementia meant for me and my father?

My parents lived for a while with me and it was during this time when we saw my mother's GP and after going through further tests, she was diagnosed by the consultant psychologist with Alzheimer's disease. In addition to my mother's Alzheimer's, we also discovered that my mother was also suffering with Macular Degeneration. The symptoms of dementia are bad enough but with the additional eye sight problem - this was a cocktail of devastating news for my father.

Although my father tried to understand about dementia, he was still in denial and would not accept that his wife had dementia. It is not easy to accept being told that someone you love has Dementia and to see them deteriorate.

My father then decided to live in a retirement flat near me with a Warden on site and 24 hour emergency help provided by a pull cord. It was a very nice flat but as my mother's dementia progressed, my father was having problems.

My mother did not like mirrors. She did not understand what a mirror was and therefore when she saw herself in the mirror, she thought there were other people in the room. She did not understand that the mirror was a reflection of herself. We had to cover all the mirrors. She also started to believe that her husband was a strange man, and would not go to bed. In her mind, she was a little girl and could not understand who this old person was. Television was also another problem as my mother found that disturbing. She thought that the people in the television were in the flat. It was generally very difficult to get my mother to go to bed and this meant many nights that my father was unable to sleep properly.

I was being called every day and night as my father was not coping. My mother would only listen to me. However stressed she was, as soon as she saw me I was able to calm her. The analogy I use is like 'rebooting the computer' – in my mother's case it is rebooting the brain. My ways of talking and understanding how to connect and calm her worked.

Talking Pierre the Parrot

One day I came across this App and downloaded it on my iPhone – 'Pierre the Parrot'.



It basically repeats everything you say and it remembers and builds the vocabulary and sentences. My mother absolutely loves this and enjoys having the same chat again and again.

This was one of the ways I was able to get her to relax and then, once relaxed, I was able to put her to bed as she would have forgotten everything she was stressed about before. 'Pierre the Parrot' was also amazing at meals times. This helped her to eat all her food. Unfortunately as my father was unable to have proper sleep, this caught up with him and one day he developed serious pneumonia and had to go into hospital.

This was the worst time not only for my father seriously ill in hospital but I had to bring my mother to my home. It was very difficult and exhausting as she needed constant attention. It was like a 2 year old child getting up to mischief every second. The only alternative was for my mother to go into emergency respite at a care home whilst my father was recovering. My mother stayed for one month in the care home.

My father decided however that he was not able to continue caring for his wife on his own and this is when we decided that it would be best to admit her in permanent care.

This was not an easy decision. Unfortunately two months later my mother fell at the care home and fractured her hip. One of the carers decided to mop the floor where my mother was sitting in the lounge. When my mother decided to stand up and walk, she unfortunately slipped.

As you can imagine we were not happy. It was then back to square one looking for another care home as my father did not want his wife to continue staying in that care home.

It was not easy and was very stressful but we eventually found another care home. I must have seen about 30 different care homes. This is when I decided, based on the experiences I had after seeing so many different care homes, that I wanted to work for the Care Quality Commission inspecting care homes and other health institutions.

It is now over a year since my mother was admitted in the new care home. It's not perfect but it ticks most of the boxes and my mother seems settled there. I still keep a close eye on things to make sure that the care home follows the care plan and medication and other matters.

Each person has individual needs and it is important to make sure that the care home follows that person's needs to be able to provide the best care for that individual.

I still however have to bring my mother home to give her a bath once a week as the care home find it difficult, partly because of language difficulties but also, as my mother still understands about her dignity, she feels more comfortable with me. I also bring home and wash all my mother's clothes and bed sheets as the care home were continually losing her clothing. I have washing and ironing every day. It's like looking after a baby.

Its hard work keeping up with all the washing sometimes especially as I also have my other work. I feel it is important however that even though my mother has Alzheimer's I like to make sure that she is always clean and always dressed looking smart.

My father goes every day to see his wife at the care home and spends many hours with her. The worst part is when he leaves her. It is difficult for my father to slip away after spending so much time with her. There is another man at the care home that looks very much like my father and this in some ways is a blessing as when my father slips away, it gives my mother comfort if she believes that her husband is still there. As he slips away he sometimes sees her telling this other man off for not listening to her. He does not respond of course because my mother is talking to him in Greek.

My father was initially upset about this but now understands this is part of dementia. When he comes home I can see that he feels lonely and depressed. Thankfully he is living with me and my husband and we look after him.

Dementia is a cruel disease and as it progresses it is very painful to watch your loved one deteriorate. There are times when I think my mother has moments of clarity, especially when she's had a good few hours at my house where she has been fussed over. She would say – "What's wrong with me?" 'I know there's something wrong with me' 'I wish I was dead' - that's when I shudder and don't sleep at night.

When we then have to take her back to the care home and when she arrives at the big gates, this moment of clarity happens again when she says – 'Oh No, Please don't take me there. I don't like it in there. I want to go home'

When my father visits his wife at the care home every day, he always make sure that he is there on time to make sure that she eats her lunch. He sits next to her and encourages and helps her to eat. He then takes her out with the car. He takes her nearly every other day to Brent Cross for her favourite cake and a cup of tea. She enjoys it at the time but 2 minutes later she has forgotten.

Each week I notice little changes with my mother's eating which is very challenging. She sometimes forgets how to chew and swallow and I have to mimic the actions. I bought a mincer recently which I am really excited about. It's a small machine; it's not expensive and it does a perfect job mincing cooked meat. You find that little things like that can make a huge difference. I shared this of course with all my Dementia Club members who were very grateful.

If I still have difficulties with trying to get her to eat then I have to bring out two other toys.



This is my mother with baby Annabel and Sweepy the cat.

Sweepy is a real looking toy cat that meows and wags its tail when you caress its head. She thinks the cat is real and this helps me to feed her.

Baby Annabel is an interactive baby doll that looks and feels very real. She loves this baby so much. The baby talks, cries, burps, drinks from a bottle and sleeps making deep sleep sounds. The care home is so grateful especially when my mother has those anxious moments.

I had to leave the baby with the care home and buy another one for when she comes to my house. At first I felt guilty using the toys because – I know that they are toys for children - but from what I have learnt from experience with people suffering with dementia, in their eyes the toys are not toys.

I mentioned earlier that I would talk to you about a new breakthrough drug. Alzheimer's breakthrough Drug.

It's called – Aducanumab.

This is good news as it is the first drug breakthrough after 25 years of research that can prevent Alzheimer's disease.

Editor note: at time of writing this drug was exciting news but after further trials and research it was found to be not successful.

Patients treated with the highest dose of this drug saw an almost complete clearance of the amyloid plaques that prevent brain cells communicating, leading to irreversible memory loss and cognitive decline. The first drug to prevent dementia could be available in just a few years, which will bring new hope to patients with this disease. Not only does the new study suggest a treatment for the disease, but shows that the build-up of amyloid plaque in the brain is likely to be the blame. The drug is likely to be most effective for patients in the earliest stages of Alzheimer's disease or those who have not begun to show symptoms. Early blood tests for dementia could pick up the disease 10 years before the first physical signs appear.

Professor David Allsop, Professor of Neuroscience, University of Lancaster said that this study shows convincingly that it is possible to reduce the extent of amyloid plaque formation in the brains of people with early signs of dementia.

Further trials need to be done on further patients and researchers are currently recruiting British participants.

Dr David Reynolds, chief scientific officer at Alzheimer's Research UK is optimistic that a new class of drug to treat the disease will be available in a few years.

Whilst this research continues, my aim through Dementia Club UK is to continue helping people living with dementia to live well and live with dignity and provide help and advice to the carers. I will also continue to raise awareness and provide a better understanding about dementia where it is required.

Whilst no one knows how we can prevent getting dementia, the only thing we can do is to make sure we lead a healthy lifestyle.

10 Healthy tips for a healthier lifestyle

1. Always put yourself at the top of the list
2. Make time for yourself every day to do something you enjoy
3. Eat regular well balanced meals (chew your food well and eat slowly)
4. Find an exercise you enjoy doing for 30 minutes every day
5. Sleep as much as you can – They say that deep sleep may be the key to prevent Alzheimer's disease. Research shows that disordered sleep increases beta-amyloid protein in the brain, which interferes with memory.
6. Keep hydrated
7. Try to laugh every day as laughter boosts the immune system, improving your resistance to disease and decreases stress hormones.
8. Always share a problem
9. Never be afraid to ask for help
10. Choose a hobby you enjoy

SO WHO REMEMBERS THE ADDRESS IN THE 6 ITEMS COGNITIVE TEST?

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The address is on Page 8.

Dementia Club UK

My aim is to continue helping as many people as possible, which is why I formed Dementia Club UK in January 2016. This is now a registered charity and has 4 trustees including myself as Chairman.

I see people who have just been diagnosed to people who are really progressed. One gentleman who attends the sessions lost his wife with dementia a few years ago. He told me that the dementia club has given him a new lease of life as he has made new friends.

As already mentioned at the beginning, I opened the first Alzheimer's dementia café in August 2013 at the Finchley Memorial hospital. The café was so popular but after one year I needed to



raise more money and therefore organised a charity fundraising event at Saracens Allianz Park. I was delighted that evening to hear that Saracens wanted to sponsor me to open more Dementia Cafes in the borough. The Saracens Dementia Club was therefore launched on 1st April 2015 and now I run weekly sessions at the Finchley

Memorial Hospital. I am still running the Alzheimer's Society Dementia café once a month and I am also running weekly Dementia Club UK sessions at 4 other venues in the Borough of Barnet.

Dementia Club UK is a place for people with dementia and their carers and families to meet and talk in a relaxed atmosphere and to share their experiences over a cup of tea/coffee and M&S cakes.

We have our own GP and nurse who attend most sessions and they offer to take blood pressures and answer any medical concerns. We also now have Harley, our dementia friendly therapy dog.

He is a very lovable Labrador and a great hit with all the members. Each session runs for 2 hours and is divided into 4 parts except when we have special occasions with musical entertainment, which includes some singing and dancing and a magician.

The first part of the session takes about 20 minutes as members arrive and settle down with their cup of tea and cake. During this time members are chatting amongst themselves. This is also an opportunity for me to do a welcome announcement and also to let them know about any news and updates on the programme.



The second part of the session we provide professional advice and information from various speakers.

If we do not have a speaker, I organise other activities such as quizzes, poetry reading, bingo and singing. I sometimes organise other special guests for example we've had MPs attend, The Deputy Lieutenant for Barnet, and we recently had a celebrity – Mr Ian Towning (London's TV Antique Expert from Channel 4 Posh Pawn).

Members brought so many items to be valued and some members were nicely surprised to discover that their item was worth a lot of money.

The third part of the session is exercise to music. As a qualified fitness instructor, I provide gentle exercises as I believe that a healthy body is a healthy brain. I sometimes organise other instructors, such as Tai Chi and ballet dance movements. This picture (above) shows a ballet dancer showing members some gentle exercises.

When I teach the exercises to everyone, I keep everyone motivated and involved. No one is left out. In one of my sessions there was a couple – her husband had deteriorated a lot in the last few months. His wife was very stressed and unhappy because he was no longer showing any interest in anything and would not smile.



On this occasion however, I played a slow Elvis song and this must have triggered a memory for him as he suddenly smiled and wanted to stand and take a couple of slow steps. His wife was so happy to see this, she had tears in her eyes and I must admit that this brought tears to my eyes too.

Music for people suffering with dementia is very important. Even if the dementia sufferer is unable to communicate, if they hear music they like, they will respond to it by singing, clapping, tapping their feet or even like in the picture, members will be motivated to dance.

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Music seems to reach parts of the damaged brain in ways other forms of communication cannot. Whilst most of the brain cells die, the last part of the brain that remains is the part that recognises music. This stimulates the brain and makes a dementia sufferer happy. My mother loves music. She loves to sing and tries to remember the words. My father plays some of the old songs she used to like. This motivates her to also get up to dance a few steps. Her favourite song is 'She'll be coming round the mountain'.

The fourth part of the session is the social activities to stimulate the brain, such as Golf Putting, skittles, magnetic darts, catching and throwing the ball to each other, throwing the ball into a net on the floor and much more. I always make sure that everyone takes part and has fun.

In the last 10/15 minutes of the session, I like to encourage a discussion, giving members a chance to share any stories, any problems they have encountered recently, any feedback about the sessions. Just before they leave, I always read a couple of jokes as I believe laughter is the best medicine. Everyone always leaves with a smile.



In a recent feedback session, members informed me about a problem they were experiencing with all their pills.

Why are pills manufactured in white and similar in shape?

They told me that as most pills are now manufactured in white, if someone for example is taking about 10 pills a day and they need to be sorted in the pill box; it is very difficult to know sometimes which pill is which, especially if you suddenly get distracted or you accidentally spill the box.

Members asked me if I could find someone to explain what is happening. I therefore invited a pharmacist from Barnet Clinical Commissioning Group to one of my sessions to see whether an explanation could be provided.

Unfortunately there was no simple answer. The pharmacist agreed that this was a problem and gave us an example with regards to care homes administering Lorazepam. As Lorazepam comes in both a low dose and a high dose and both dosages of the tablets are white and the same size, this creates problems. In this example, the care home administered the wrong dose to the person.

I would still like to pursue this matter and hope that something can be changed especially if we no longer have any European laws that restrict us. Perhaps more pills can either be coloured or have some identification mark.

I would welcome any suggestions

What is the impact of physical activity on people with dementia and their carers?

Dementia Club UK recently commissioned Middlesex University to conduct research to evaluate the impact of exercise and other psychosocial activities on the well-being of people with dementia and their carers in a community based setting.

The funding for this research was awarded through Saracens Sports Foundation which sponsors Dementia Club UK. A fundamental aspect of the research was to evaluate the support provided by Dementia Clubs as a service in the community.

The results of this research, which will be announced soon, will help develop new services locally and nationally in the future.

My Aim in my Campaign

My aim in my campaign is to continue raising awareness about dementia, to promote a better understanding, and to stamp out any stigma associated with dementia.

Whilst there is no cure for dementia, I want to try and help as many people living with dementia to live well and live with dignity, and also to help the carers to have some quality of life.

Dementia Club UK's company objectives aim to do just that. I offer advice and support during difficult and challenging times. People can call me any time to discuss concerns and I can also do home visits and arrange to meet elsewhere. I want to continue to help more people and our aim is to expand our services nationally.

From what I have seen and experienced, I would personally like to see more people living with dementia to continue living in their own homes with their loved ones, and with a carer provided for their individual needs. Unless of course it gets to the point when they need nursing care. If you have a spare room in your house, this is the best option to have a live in carer to care for your loved one. You can be assessed if financial help is required.

We already have properties which are warden based with emergency pull cords in the rooms and although these properties are fine for people with no mental health conditions who can still live independent lives, I would also like to see more developments, to also include carers and nurses, for our ageing population with mental health conditions.

The advantages to this are that a couple can remain living together instead of living apart. I have seen the devastating affect it has had on my father being separated from his wife.

You would also have the peace of mind knowing your loved one would be receiving tailored care according to their needs.

It would also mean that we would no longer need residential care homes. We would only need nursing care homes. This would not only save on a lot of costs but this would further relieve the pressures on our hospitals.

Raising awareness about dementia is important so that there is a better understanding of this terrible disease. For the past 2 years I have organised a Dementia Awareness Day during National Dementia Awareness Week at Brent Cross Shopping Centre in the centre point. I also invited other charities to participate during the day to help raise awareness. People are beginning to approach and ask more questions now about dementia but there are still a lot of people who are too frightened to ask.

Is anyone a dementia friend or Champion?

One of the ways to help raise more awareness is to become a Dementia Friend and Dementia Friend Champion.

Dementia Friends is about learning more about dementia and the small ways you can help - from telling friends about Dementia Friends to visiting someone you know living with dementia.

A Dementia Friends Champion is a volunteer who encourages others to make a positive difference to people living with dementia in their community. They do this by giving them information about the personal impact of dementia, and what they can do to help.

I'm pleased to hear that many companies, supermarkets and other organisations are becoming dementia friendly. The latest is London Heathrow Airport, which announced its commitment to becoming the world's first dementia friendly airport. As a society we are desperate to create a better understanding.

The Virtual Dementia Tour

On the 13th January 2016, the Virtual Dementia Tour training programme was launched at one of the care homes in Berkhamsted. The creator P.K. Beville flew in from America to be part of the launch. The Virtual Dementia Tour is designed to give individuals and care home staff the ability to help identify with and understand the behaviours and needs of people that live with a dementia.

The experience is based in a converted lorry with a tent attached. Participants will wear gloves, glasses and headphones to distort surroundings.

The Borough of Barnet will soon be hosting the same and I have been asked as the ageing well champion, to attend and participate in this programme so that I can provide my view.

The Virtual Dementia Tour is said to be a scientifically proven method of building a greater understanding of dementia. Whilst I believe the Virtual Dementia Tour is a step towards providing some understanding of dementia, I am not convinced that we can rely on this being a true understanding of what dementia is.

It would be easy to ask someone who has just been diagnosed with dementia to be able to explain what they are going through but a person who is more progressed will not be able to explain their experiences. We can only guess by the actions we see.

Dementia Poem by John Steward

I want to bring my presentation to an end by reading you this poem.

However as it has 16 verses I will just let you have a few lines. It's written by a person suffering with dementia and describes his memories, how he is feeling and how he sees other people. I suspect it was written before his dementia progressed. It's a gripping poem.

The poem has been removed for copyright reasons but can be read on the following link:

<https://www.smh.org.uk/word-of-the-week-110316/>