Good Morning. I am here today to talk about the challenges of living well with Young Onset Dementia and, in particular, the coping strategies that I have put into place to cope with my Fronto-temporal dementia in my journey through its weird and varied landscape. Due to how my dementia affects me, please forgive me for reading from my notes. I am aware that the art of a good talk is to use Brevity. I’ll be covering this in much greater depth on page 25!

I was diagnosed with fronto-temporal dementia in December, 2012 which caused me to have to retire from work.

In my working life, I had a number of interesting professions. I was a musician in H.M. Life Guards Mounted Band, where I was a State Trumpeter and played saxophone. I had to be able to play these instruments while mounted on a horse. Not easy to do, as I had to steer the horse with my knees, both hands were needed to play the saxophone!

Next, I was a Village Policeman in the Kent Police and, on my retirement, I became a Driving Instructor. I finished off my working life as a Driving Examiner for cars, tractors and taxis.

All these jobs required a very organised regime and I have always been a meticulous and methodical person. The onset of the fronto-temporal dementia hit me very hard as life became increasingly difficult due to my Executive Functioning being affected. Now it is very difficult for me to put things in a correct sequence, even down to the correct order of the letters in the alphabet, which is something learnt at an early age.

I am very involved in music making and most weekends I can be found on a bandstand somewhere in Kent, or further afield. It has become increasingly difficult to read the music correctly and, like words, it is now harder to get the information off the page in the correct order and sequence

During 2010, it became increasingly apparent to my family, my work colleagues and to me that a change was occurring. I was starting to mix up my words, I was getting confused with regard to things that had happened in the recent past and I appeared to be just becoming vague when in conversation. At the time, I was employed as a Driving Examiner. The nature of my work during the driving test of candidates required me to remember what, when and where things had happened in order to debrief the test and then accurately write up the report afterwards. I noticed that this was becoming increasingly hard for me to do, and needed far greater and more intense concentration to do so.
I made the first of a series of visits to my Doctors practice. I was given the Standard Dementia Test which I appeared to have no problem with. Dementia was ruled out as being the problem. It was suggested that I might be suffering from depression. Having had a nervous breakdown and been clinically depressed in 1990, I knew how I was feeling had nothing to do with depression.

Over a number of visits to my Doctors practice, various theories were suggested. These included Speech Therapy, visiting a Psychiatrist or that I might have a form of Migraine (although I wasn’t getting any headaches or light phobia). There was the ever constant suggestion that I was depressed. The idea that I might have dementia was never on the G.P’s radar. Why would it be? Here was someone who was passing the Standard Screening Test and was still in is his 50’s.

Understanding around Young Onset Dementia has improved greatly over the last 5 years but still has a way to go. Of course, when most people in society think of dementia, they think of Alzheimer’s, an older person and a person in the later stages, unable to think and care for themselves. I have lost count of the number of times that I have been told I don’t seem like someone with dementia because I don’t look or behave like the stigmatised perception of a person with the condition.

About a year ago, I had an abscess on my tooth and visited the emergency dentist at the hospital. I had filled out the form and on it I put I had dementia. While the dentist was treating me, I got a bit mixed up with my words and apologised saying that it was the dementia getting in the way. He replied “You haven’t got dementia”. I asked him why he thought that as I had put it down on his form. He said I didn’t look like someone with dementia. Now, how he could make a dementia diagnosis just by looking at my teeth I’ll never know!

After 18 months of my symptoms getting slowly worse, with no remedy being found, I visited another G.P. within the practice. He repeated the Standard Dementia Test which again did not flag up Dementia problems. The G.P. said that certain types of dementia did not show up using the standard test and, this time a referral was made for me to the Memory Clinic. It had now become impossible for me to continue working and although I made two attempts to go back to work, both times I only managed a couple of days before my Manager, seeing that I was not coping, suggested that I return to sick status.

I subsequently attended the Memory Clinic where a series of in depth tests were carried out. I also underwent various scans. In December, 2012, as a result of these tests, I was diagnosed with Fronto-Temporal Dementia. It was clear that there was a problem with regard to my Executive Functioning. This was the ability to put things
correctly sequentially when given in a random order. The various scans did not show up any significant abnormalities. I was assured that this was not unusual as, in 10 to 15% of cases of Fronto-Temporal dementia, the changes in the brain do not show up on the scans. As a result of the diagnosis and there being no cure, I was forced to retire from work.

Although it is never good to get a diagnosis of dementia, it was a great relief to finally establish the cause of the challenges that I was having in everyday functioning. I was now able to explain to family and friends the reasons why my demeanour and behaviour was sometimes different from the person they all knew well. However, the way I looked at it is the fact remained that I was the same person the day after my diagnosis as I was the day before diagnosis but I now had a label that I was able to attach to the problems I was encountering. I had reached a crossroads in my life. I could give in, submit and deteriorate or I could fight back. Life will always throw challenges at us but, as long as we get up and fight one more time, we are not beaten. Having been diagnosed with dementia, this has given me the opportunity to meet a diverse selection of people and champion the cause of better understanding of dementia in the general populace. This helps to improve conditions for people affected in and around a diagnosis of dementia.

I find that when dealing with other people, quite early on, I inform them that I have dementia. That way, they can help and understand when problems or challenges raise their head. Let’s face it, if we have difficulties with our hearing or sight, we would soon let people know to allow for ease of inclusion and understanding.

Let me outline my journey through the system in the first year after my diagnosis. I took part in a Group Cognitive Stimulation Therapy course and a further One to One course. The One to One course was far more beneficial to me as it was tailored and adapted to suit me on a more personal level. In the group course, I was the youngest by at least 15 years. Many elements of CST are to do with reminiscence back to our youth. During one of the sessions, we were shown pictures of people to identify and historical events. Examples were Edward V111th and the Queen’s Coronation. Now, I was born in 1954 which was a year after the Coronation in 1953 and Edward V111th abdicated in 1938. My first real historical memory was when President John F Kennedy was shot which occurred in 1963. In one of the music sessions, we were played Glen Miller which, of course, was from the 1940’s. Really, my music memories only start with the Beatles, Rolling Stones, The Monkees, Jerry and the Pacemakers, and the Dave Clark Five. Basically, the 1960’s onwards.
There is no doubt that CST is very beneficial to all those people who take part in it but, surely, it must be relevant to the age group of the people taking part. Certainly, it is important to look at having a Young Onset Dementia CST group with activities that are more relatable to for the participants age wise. I would suggest, by very definition, that the subject matter needs updating across the board for all those taking part to keep the sessions effectively stimulating and being therapeutic to all.

Due to the Fronto-Temporal Dementia, I am constantly having to find coping mechanisms to deal with problems in my life as they arise. The overall effect that my Fronto-Temporal Dementia has on me can be summed up in the famous Morecombe and Wise sketch with Andre Previn, where Eric Morecombe said “I’m playing all the right notes but not necessarily in the right order!” This applies to all aspects of my thinking process where a correct sequence of events is required. I will outline some of the areas where I experience these difficulties but this is not an exhaustive list by any means.

**Writing**

Increasingly, when writing, words do not come out on paper how they are in my brain. Letters get mixed up, sometimes doubling up in a word. The formulation of letters sometimes comes out wrong. I have to pause to make the shape of the letters correctly. Words get put in the wrong order and, when writing my signature, I have to concentrate and write it slowly. To help me address these issues, I use the computer which has an automatic spell check facility or underlines words not grammatically written. Items that would have previously taken me 15 to 30 minutes to write now take hours of intense concentration with frequent breaks due to mental exhaustion.

**Reading**

My speed of reading has reduced greatly. Some words no longer make sense, even simple ones. Long paragraphs cause me to me to lose their continuity and have to be re-read. When returning to the book, whole sequences have to be re-read. Unless the plot is simple and the characters are clearly defined, then nothing makes sense. Sometimes getting the words off the paper is very difficult and they need reading a number of times before I can comprehend them. To cope with these problems, I have learnt to read slower and re-read sections to ensure comprehension. I try not to read books that use flash backs and I make sure the type is clear and well defined on the page.

When filling in a form, because this is a combination of both reading and writing, numerous problems are encountered. I need somebody to help me to interpret the
meaning of the questions and to ensure I am recording correctly the results that the form is asking for.

**Routines**

The first couple of hours of each day tend to be foggy and it is hard to concentrate on anything. As the day progresses, I need to have a well established routine within a familiar environment and a clearly defined written list of activities that are to be undertaken. Without a list, I am all at sea and adrift. If there are more than a couple of things to think about, the mind freezes and the ability to sequence correctly disappears, leaving me unable to do anything. Cups of coffee get made but then forgotten about in various rooms and new ones are made without the previous one being drunk. The lists that I make need to be kept in my pocket because, if they are put down, I am liable to forget where I put them. As the day progresses, things generally improve but then go into a decline towards the latter part of the day. When I am in a strange environment, with a change of routine, coping becomes very difficult. Something that would normally be routinely achieved in minutes, like getting ready for bed, can become a serious challenge and take an inordinate length of time. It is useful if I have somebody with me to guide my sequential thinking processes.

**Conversations**

Conversation, particularly in groups of people, can be very confusing and challenging. It is difficult to understand what is being said and following the flow of the conversation is hard. Even in a one to one situation, I can find it difficult, as people don’t seem to comprehend just what I believe I have clearly outlined or said. If I am interrupted when talking, then I completely lose the thread of what I was saying or thinking and I am unable to resume that line of thought without great difficulty. To cope with this, I listen carefully to what has been said, repeat it in my mind, think carefully about what my reply needs to be and only then, do I give a reply. In effect, I have the conversation twice over. This can be very tiring and sometimes it is easiest to remain quiet or retire from the conversation. There are frequent occasions when the wrong word comes out. Often it is very similar to the word I mean but sometimes not at all. Only the other day, I meant to ask my wife to pass me the vinegar but I actually said “Please pass the concrete”! Sometimes when I am talking, the word completely evades me almost as if it has been tipp-exed out of my mind.

**Emotions**

I have noticed that my emotions have become heightened and much more difficult to keep in check. With all my previous professions, I had to develop an ability to not be
affected by emotion and to be in good control of what I was thinking and saying. These days, this is becoming increasingly challenging to keep under proper control and I have certainly become more tearful and easily affected by things that are happening around me. My patience is now extremely short and it is very challenging to not say exactly what I am thinking and say my thoughts just like a young child does. To cope with this situation, I am very open with people about the fact that I have dementia and, due to this, generally people do accept and understand the difficulties that I am facing. I encourage people to laugh with me at the various strange and, sometimes illogical things that I say or do. Humour is by far the best coping strategy that I have found in the confusing world of dementia.

Coping strategies can come from all sorts of areas around us and often come up in conversations with other people who are living well with dementia. One such idea came from my fellow Dementia Service User Envoy in Kent to do with coping with his morning routine. In the bathroom, he has a large ice-cream tub that he keeps his toothbrush, paste, electric razor, soap, flannel and other items to do with his morning rising routine in. He takes them all out of the box and places them on the window-sill. As he uses each item, he places it back in the box until he has no more items to use. This way he can be sure that everything has been done ready for a new day. I belong to a number of groups for people with all types of dementia and it is amazing how many good ideas come out of just talking to each other about the challenges that they face and how they deal with them. Not all of the ideas that come forward will work for everyone but the more we discuss things around dementia, the better likelihood there will be of finding solutions. My way of dealing with dementia is to live my life to the full and to get myself out and about as much as I can, while I can.

In the spirit of “Living Well With Dementia” I have recently taken part in a Hovercraft Driving Day, a Segway Safari Day and a Tank Driving Day. On the latter, I got to drive 4 different armoured vehicles, including a Chieftain tank and do a session on Quad bikes. It was fun to see the instructors faces when I declared to them that I had dementia! I have to say, they watched my every action very carefully! I have also taken a Helicopter flight over London and a Fixed Wing Micro-light flight over Kent. The Aviation Authorities were pleased to know that I was not piloting the helicopter!

It is my belief, that when life throws challenges at us, we should face them head-on and fight back. I have adopted the daily mantra of “I may have Dementia but Dementia does not have me!” It is my belief that dementia comes in CANS. We have to focus on the things we CAN still do and in the famous words of Winston Churchill “Never, Never, Never, Give Up!”