

FPOP FTD Presentation 3rd July 2018

I was diagnosed with Fronto-temporal dementia in December 2012 as it was apparent during the tests that I had difficulty with sequencing and my executive functioning. Oddly, it was a relief to get a diagnosis, but I think it was because it confirmed that the challenges I was having had a genuine and medical cause.

Of course, like everyone does after a diagnosis, I went onto the computer and researched what the condition was about. There I found a long list of thoroughly anti-social behaviours that I was likely to develop alongside a prediction of me losing Insight into the fact that I was doing them. Having worked as a Police Officer, Driving Instructor and Driving Examiner, I had always prided myself on my ability to be tactful, understanding, empathetic and have good self-control. What I was reading seemed to suggest that I would lose the very essence of all that I believed and stood for in my interaction with the world around me. Certainly, the predicted average life expectancy of two to eight years from diagnosis was, as they say, a bit of a bummer and would certainly stop anyone in their tracks! I was very aware that what I was reading should not be treated as a one size fits all and yet it stated that people with FTD lack insight! Certainly, when looking at the condition, it is not just black and white but far more different shades and grades for each individual. I believe the word Insight should be changed to Awareness as this far better describes the interaction within society and the thinking processes of the brain.

So, it is now five years since my diagnosis. I'm still here and it is not a hologram standing before you! Yes, there have been changes but not in the extreme ways suggested within the diagnosis criteria and the information out there on the internet. Where am I now? No, I know I'm at the FPOP Conference in Cambridge, that's not what I mean! What I mean is what effect has my FTD had on me.

I can be far blunter in my responses and less sympathetic. I seem to be losing the filter that we all have to prevent a controversial comment being said or action taken. Most of the time I am aware of this at the time or just afterwards but occasionally not. I can normally be aware of this fact if it is pointed out but sometimes not. Although it is contrary to what is generally assumed, my recent memory of events is now in a decline although this is suggested to remain relatively intact until the later stages of FTD. Both the memory issues and the loss of filter in my brain can cause me to interrupt people when they are already in conversation or concentrating on another activity. What I have been thinking or believe to be important has to be said or acted on there and then. If this does not happen, then I can become annoyed and agitated. It is difficult for me as it can feel that I am being ignored even though this is not the case. Sometimes I start a conversation in my head and continue it out loud and then I get very frustrated when people don't understand what I'm talking about or don't seem to have been paying attention to me, although I haven't actually said half of what I'm talking about out loud. I have only recently become aware of this when my family have pointed it out.

My behaviour has not deteriorated to the examples shown on the slide. I do not run around with no clothes on or engage in any of the sexual deviations suggested, he says checking his trouser flies are done up! I do sometimes have the desire to compliment women I don't know on their attractiveness or reach out to touch them while paying them a compliment. Sometimes I feel the need to tell people how obese they are but, as yet, I still haven't actually done it although it has come very close. I find the list of likely behaviour symptoms of FTD acts as a danger warning signal to me of a possible deviation by me from societies accepted standards and still gives me awareness or Insight that this behaviour would not be acceptable. This awareness helps me to put in place coping strategies in public like making sure my hands stay in my pockets to prevent touching. With the exception of applying gaffer tape to my mouth, I have yet not found a physical strategy to stop me saying exactly what I am thinking!

Another big challenge is with Sequencing and Task Initiation. I am aware that something needs to be done, like when I was writing this talk, I have great difficulty initiating the task and breaking the inertia. It is very hard to put my thoughts in a logical and good sequential order and things get put off time and time again because I find this so hard. Procrastination is the biggest nation in the world and I am a fully enrolled member!

When it comes to reaching a decision on a diagnosis around dementia, it is right and proper that there should be a set down list of the criteria in order that the correct diagnosis is reached. I feel some of the things listed in the criteria and written on the internet relate to people in the later stages of the condition and it should be borne in mind that there can be great variations in the nuances the ways the condition presents. From my personal experience of living with dementia and chatting with friends with an FTD diagnosis, I have found that sometimes a hard and fast criterion cannot nor should be adhered to without the various variations within the condition being considered.

Certainly, when a person is first diagnosed with FTD, it can all look very daunting and bleak that there is no hope. I found that I drew a line in the sand, accepted it as what it is and vowed to move forward with my life in as positive a way as possible. This includes educating as many people as I can around me about the true ramifications of living with FTD. Certainly, as there are no tablets available to help with the condition, I stress to people the various Psychosocial Interventions that are out there to help keep deterioration at bay.

In conclusion, I don't treat the diagnostic criteria and media information about FTD as a tick box exercise. Yep, got that, got that but still working towards getting that but rather as a warning to me to keep my behaviour under control.

Thank you for your attention to what I have had to say today and I hope it has been useful for you.