**Interview 11**

Thank you so much for agreeing to take part in the CALM research study. Below are some questions to help us understand your experience of having MND and managing it daily. Please feel free to provide as much or as little detail as you like. If you feel that some questions are repetitive, and you have already explained something before, you can skip over these questions. The information you share with us will be kept confidential, so please feel free to share as much as you would like to.

1. Can you tell me about your experience with MND? Wherever you would like to start, either about diagnosis or when you first noticed symptoms to your experience now.

*When I first noticed that I was slurring my words I never ever thought it was anything serious. On visiting the Doctor I had assumed that I would leave the surgery with a prescription or antibiotics, job done. Instead I was referred to a neurologist. I had noticed the decision to refer me to a neurologist was made after my Doctor and a trainee showed special interest looking at my tongue. I stopped off at home on my way back to work to inform my wife of the outcome and of course, we paid special interest to my tongue. On presenting my tongue it could be seen to be “twitching” (I now know it’s called fasciculations). At lunch time back at work I took the opportunity to ask Dr. Google typing the words “twitching tongue” into the search engine. The only result that turned up was MND and as you can probably imagine I was mortified. On returning home that evening my wife greeted me with a question “did you google it”?*

*We were both devastated and kept asking the question why?*

*My thoughts were “I won’t see my grandchildren grow up and have there children”*

*I was unable to tell our children and my wife had to do this on my behalf and then it is there turn to be devastated and confused.*

*I quickly came to accept that I had MND and my thought process was to enjoy every day especially whilst I am still reasonably fit and able. I soon learnt that as things happen you adapt to overcome them, up to a point.*

1. Have your thoughts and feelings changed since you were diagnosed or are they the same? (If different, in what way have they changed?)

*No. My thoughts and feelings did not change on diagnosis as I was pretty much convinced that I had MND. I had revisited my Doctor to ask him to explain the Neurologists first report and he informed that on my first visit to him two months earlier he knew it was Bulbar onset motor neurone disease. Having said the above I felt that now I had a firm diagnosis I could tell more friends and family my situation rather than hiding it from most of them which I took as a positive.*

1. What’s it like to live with MND now? What are your main concerns/worries/problems you face on a day to day basis?

*I have accepted that I have MND and have more recently realised that as things progress you adapt the way things are performed. A simple example is that to open a breakfast bar, why struggle, pick up a pair of scissors and it is so much easier.*

*The main worry is how the disease will progress and how I will overcome the challenges it presents. My wife tries to think of all possible eventualities but I personally do not like to think too far ahead and overcome the challenges as they start to present themselves. My thoughts are that (at the moment) the progression doesn’t happen overnight and when something starts to happen I can think, discuss and use the online information that is available to understand and implement different strategies to overcome the issues.*

1. Are there any emotional concerns or difficulties you go through, either in the past or at present? Please can you describe these experiences for me.

*The only emotional issues I have had were right at the beginning when I realised that I almost certainly had MND. Time was the healer here along with support and understanding from my wife and the immediate family.*

*As I have said in Q1 I was devastated and emotionally distraught. I can only think of one other occasion that bought me to tears.*

*The disease can be frustrating when you realise that something which use to be an everyday occurrence you now find difficult as things progress. I have learnt to accept and adapt, sometimes with some resistance not wanting to admit defeat.*

*I also accept that I may view things differently when the disease has progressed to the extent that where I become very reliant on other people every hour of the day to help me. As I have already intimated, I try not to dwell to much on what the future may hold for me.*

1. Can you tell me about how you cope with MND on a daily basis? If you find yourself having any emotional concerns or worries, do you have any ways of managing them?

*My speech is now almost non existent but as time goes by I have been relying on a text to speech app. I only this week met up with a couple of friends and for the first time I took my I pad along and mostly used that as a means of communication. They were impressed with the app.*

*I suppose maybe the way people react to me is a concern but as of now I have found people to be very accommodating and accepting. I have experienced people talking to my wife when asking me a question and because I cannot talk people thinking I cannot hear but I smile at this and just think “oh well”*

1. Can you tell me about any support you feel you have? Or people or things that have helped you?

*Since diagnosis I have had a tremendous amount of professional and personnel support. I cannot praise enough the support I have had from the NHS system. This includes the Neurologist, palliative care Doctor / nurse and the District nurse. I also have a speech and language therapist along with a contact within the MND association. On a personal front family and friends have been a massive help fully accepting what the disease is about and accommodating as necessary. I guess they have also given me emotional strength that this is not the end of life and there are people and equipment available to continue to make life comfortable.*

*The MND association has also been a considerable help with the web site packed with useful information and contacts including links to external sites. Also going hand in hand with the association is the forum, once again packed full of useful information given out by fellow sufferers.*

1. Did you receive any support from organisations or healthcare professionals to help with how you were feeling? (If yes, what did this support look like and what was your experience of it? If no, would you have liked any professional help/support?)

*No, not directly but I feel that if I had requested help because of emotional issues then they would have been only too pleased to point me in the right direction. I have monthly visits from the district nurse, two monthly visits from the Palliative care and they always ask how I am feeling I guess giving me the opportunity to say something.*

*The MND association has a huge amount of information available and I have no doubt that would include emotional issues (?)*

1. What do you think about using online support tools to help you with how you are feeling and what you are going through? Are there any things we need to keep in mind/pay attention to if we want to design something like this?

*For me it is another avenue to explore if I ever had the need to. My thoughts are that you can never have enough information and guidance.*

*Things to bear in mind is that it has to be simple to navigate. I know people (not MND) who are totally lost when it comes to things like online tools hence the reason for it to be simple to navigate to encourage people to use the tool if they feel the need.*

*Something else to consider is that they say this disease is “rapidly progressive” so we are certain to be challenged by new things as each month goes by whether that manifests itself in a physical or mental way.*

*I image a (behind the scene) complex flow chart to help people find a solution to their particular issue along with perhaps links to external sites giving access to more details around their issues.*

*I have always enjoyed (if I can call it that) reading through real life scenarios and how a problem/feeling was overcome or minimised to an acceptable level.*