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.

My sister and 2 brothers died from MND. I was with both my brothers so I know what it can do. It is wicked and ugly. Many times I thought if I got it, I would kill myself first before suffering like they did. Now I am70 and have been diagnosed. We are doing all we can to keep healthy. After over 2 years of seeing a specialist who said I DID NOT HAVE MND, he finally stated I had it in September 2018. It was a bitter end to the MRIs, x-rays, scans and spinal tap. We have no confidence in our medical team and for the most part we are ignored and voided. We have many things we liked to try but the answer is always the same NO. So we make our own world and do the best we can.

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

So many changes, so many feelings, it’s difficult to live with, dying, nothing you can do about it,. We were so adamant to find out what was wrong but…After that was no help.

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?

How to get around?

What to eat?

What will stop working

Calls, appointments, nurses, doctors, there are so many of them and we never see the same one again. Our specialist is an ass, our GP is a great person whose hands are tied, he cannot help us. We work with our Dr in America who is kind, informative and helpful but thousands of miles away.

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.

Cannot cut meat, cannot do buttons, cannot tie shoes, forget where things are, lose items, no sense of directions. Loss of thoughts, unable to follow through, cannot understand what I read, get angry easily, uncontrollable anger, useless, pathetic

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?

I have my wife, a few friends no family. It is lonely. It is hopeless, trying to keep a good attitude but it is difficult.

Losing too many of life’s pleasures, depending more on others as the day goes by.

Some days I only sleep. Lost appetite

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

My wife

My friends

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?)

Nothing

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?

Online is hard to use. Only one hand. Hard to understand and follow through. Cannot do it myself