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.

I was diagnosed on 05/09/2016 but felt symptoms over a year before. Since being diagnosed it has progressed very fast. I was referred to the local neurological centre who helps with diet and occupational therapy. But it seems there is no treatment for MND to slow down the progression of the disease, or arrest it.

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

My thoughts and feelings have changed. The condition is the worst and I am always trying to think about improving it but no luck. I feel that since diagnoses and checking MND condition online it rapidly progressed far more than expected, so this is something to do with negative thoughts and brain activity. Reading through this questionnaire adds to more negative thoughts.

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?

Everything is difficult. My main concern is breathing difficulties – I use a nippy machine almost all the time. This affects my eating and drinking capabilities severely.

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.

My concerns are to do with my wonderful family, especially my wife who is my carer too and looking after me does affect her mentally and physically. I am very emotionally concerned and try to be positive and looking forward to recovering so I hope a research team can find a cure. My family is very concerned and are extremely emotional about my condition.

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 try to remain positive – which can be difficult as I try to find ways of improving this condition. There is nothing in the UK but there are in other countries, like USA, Canada, Israel, Australia, The Netherlands, etc. where they have treatment, drugs and positive attitude. Here in the UK it seems that all neurologists do is monitor the condition and record it. No treatment, no drugs except Rilazole, no suggested supplements, no suggested exercise, no positive brain sessions.

Other concerns are that diesel fumes may cause MND, see here https://www.medicalnewstoday.com/articles/321057.php

It would be useful that [charity organization] could produce a location map of where MND is more common and align that with areas of pollution.

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

My wife is my biggest support and I have the following equipment – 2 Hoists, Power wheelchair, Stair lift, plus other things like commodes, ramps and frames. I also bought a wheelchair accessible vehicle so that I can get out and about.

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?)

I get help from the dietician and occupational therapist from the local neurological centre. We have just been close to a local hospice who will provide carer help when we request it. I attend the hospice neuro sessions almost every Thursday, which provides a very good community spirit for those of us with neurological problems.

8. 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?

I am able to use an ergonomic mouse using both hands and I have 2 screens which helps. I also use a non-screen keyboard because I can’t type.