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 first noticed a weakness in my trunk picking up boxes to help my stepdaughter move house. Shortly afterwards I realised I could not run for a bus and when skiing could not get up after a fall unaided. Two months later I got my diagnosis, probably a year after initial onset. The disease has affected muscle progressively from the legs and trunk now to my arms and hands, but my neck muscles, breathing and swallowing are almost unaffected. After the initial shock, I decided to accept the illness and that there would be no cure in my lifetime and probably little change in treatment from the one medication, Riluzole. with a rough estimate of life expectancy of up to 10 years I could plan to do some travelling whilst that was still possible and to plan what we could financially. I decided not to dwell on the past but concentrate on what I could do and now look back with fondness at what I achieved in my lifetime and the many activities I took part in without regret that I can no more. I am now five years in since onset and now without the use of my arms and only one index finger and thumb. I have written my life story for my grandchildren and others and life is now getting harder with the need for much more care, technical difficulties, for instance using computer and dependence on others. I can for the moment still get about on local buses and adapted taxis.

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

I tend to live much more for the day rather than planning ahead. This means I tend to make better use of my time but I’m rather hopeless at remembering things happening in the future. Fortunately my wife is a great planner and helps me make up for this. I am, if anything, more calm than I used to be and I have learned how to be very patient.

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?

Living with MND now significantly more frustrating than even a few months ago when I had full use of my hands. I have used computers since the early 1980s, and although I use a dictation program, it is not perfect. My wife is also disabled and is finding it difficult not to take on too much responsibility for me. I have a live-in carer, but now require hoisting and turning twice a day, when dressing or undressing with a second carer. I feel I am changing from a person into a patient and my mood is becoming slightly depressed.

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.

I have seen a counsellor weekly for the last three years, which is now helping me to keep level. However, there is no doubt about my increasing concern for how I will fare emotionally from here on. I already feel that I am on the threshold of “the waiting room”, filling time for the sake of it most days, despite trying hard to think of activities and projects that would give me pleasure. There is also the concern of the very significant cost of live-in care, if I survive another five years, as is possible.

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 do not have any very close friends in the neighbourhood, so use the services of my counsellor weekly. This is a significant help. My wife and I do discuss issues, though I am aware of the pain for her in doing so.

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

In addition to the support mentioned so far, I have support from medical professionals and in particular, an MND coordinator (part-time) for [name of location]. The local MND a group has regular support group meetings which we both attend and which have been particularly helpful. I have an MNDA visitor who calls approximately every two months and is helpful in raising issues with others and suggesting financial assistance avenues.

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?)

In addition to the above, I would also mention my occupational therapist who has been brilliant at assessing my needs and getting in equipment quickly, usually just before they were needed. This has given me more confidence in the care and support I am given. also the community nursing professional based at the local hospice has been very alert to both my and my wife’s emotional needs.

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?

This is a little hard to get my head around as I would be surprised if online support tools can go as far as an empathetic human presence. Probably the most important factor in my keeping going emotionally has been the love I have felt from many people, whether professional, family or friends.