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.

First noticed fasciculations in my arm February 2005.

Diagnosed by [name of neurologist] at [name of hospital] in October 2006.

Now have weakness in both arms, hands and neck. Speech and eating are affected.

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

Kept it a secret for first 4 years. Only my sister knew.

I tried to ignore it.

I now accept it but always try to resist the effects and progression.

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?

My biggest concern is if I ever need to give up driving it will be life changing.

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 concerns about being single. My partner has become more distant as symptoms have progressed. She avoids helping with my difficulties.

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 concentrate my thoughts on positive things.

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

My sister, [name of person] has supported me 100%

[charity organization] are amazing.

[name of doctor] is the best neurologist ever.

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?)

Probably available but never thought it would help.

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?

Not something I’ve ever considered.

Recently used MNDA Forum.