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 symptoms around September 2001 I kept falling over. Went to doctors around October and was tested for arthritis in my left hip as I’d had an infection in it when I was young.

Had a second opinion around November as I wasn’t happy with my GP. Went to see a neurologist and was in [name of place] for further tests in May 2002 when I was diagnosed.

Arms started to deteriorate but I managed to keep walking with assistance until 2017. Only had to stop due to breathing being affected.

Arms are pretty useless now; legs are still quite strong I can lift to help with pad changes and rolling.

Since 19th July after a routine visit to [hospital] for breathing checks. I was admitted with high carbon dioxide levels and low oxygen levels. Now have to wear non-invasive ventilation overnight and as and when I require it during the day.

In hindsight I think symptoms may have started at least a year before I thought anything of them. I had had a few tripping incidents but put it down to tiredness. Also, my sense of smell seems heightened to the point I smelt carbon monoxide due to a faulty boiler.

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

When I was diagnosed, I had a complete fighting spirit and went out as much as I could. Since having to have the non-invasive ventilation and my speech being affected, not being able to walk I have suffered from severe anxiety and haven’t been mentally strong to go out.

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?

Not as easy as it was at the beginning. I now require 24hr care and suffer from anxiety and worry.

Main worries are people not understanding me if I need help or something is wrong.

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.

At first emotionally I was strong and fought really hard to maintain as much independence as possible.

Since my speech has deteriorated and I need the ventilator it’s changed my mental state. It’s a lot harder to build my trust in new carers and the anxiety makes it even harder.

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?

Every day tasks you get used to having people help you. However, if something goes wrong i.e. a carer is off ill I then get extremely anxious about who I might be having.

It’s emotionally difficult not being able to physically help my son or my parents and siblings and friends. Not being able to hug people is hard and wrapping your own presents. Not being able to hold and play with my nephew.

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

I have great support from my mum and my son. I have two carers who I have had for a long time. One for nearly 7 years who I trust completely and who knows me inside out.

Having my communication device has been brilliant. Being able to type what I want to say if people don’t understand me. I can text, use environmental control to control the TV, skylights, and other things. I can text and get onto the Internet and use programs like word etc using eye gaze technology.

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 had some time in the local Hospice when I became mentally and physically ill after being told you need the ventilator and you can no longer walk because of this. They were very good but I do feel that more support could be given.

I know I can ask for help if I need it.

I feel that when it comes to getting the right carers there are major loopholes. It took me 6 weeks to get out of the Hospice because of Continuing Health Care and during this time I became so tearful and emotionally affected because I was being told I could go home one week then the next it was soul destroying.

Being able to get the right carers for you is a constant uphill struggle. It is important to trust your carers and being given time for them to be trained is a constant uphill struggle with funding etc.

It’s very important to have carers with brilliant communication as my speech is harder to understand and times when I don’t have my communication device I need to know they will understand any problems I have. I have had some experience of carers who really struggle and it can set my anxiety off. I have also had two live-in carers who were totally unsuitable for me and that sent me mentally downhill. Crying, not eating, not feeling safe in my own home. Time is needed to find the right carers for people and enough time to train people so the person feels safe.

If the care you receive is not right or settled your mental health drops very rapidly and can lead to you feeling like you could easily give up.

Continuing Health Care are a nightmare and do not help make things easier. I’ve been home from the Hospice since November 2017 and my care still isn’t completely sorted out. It can feel that it doesn’t matter about the quality of care just as long as you have care and it’s cheap enough. I feel quality of care is vitally important to your mental health so having the right care providers is essential to people coping and living a happy life.

1. What do you think about using online support tools to help 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 support would be helpful but you have to bear in mind some people don’t like to talk about the illness and how it affects them.

Sometimes it’s hard admitting you need help so perhaps to know there’s someone you can contact yourself online would make it easier to ask for help.

It may also help to be able to talk to other people going through the same issues and having people listen and perhaps be able to help with things like the care problems. I feel the key to coping well as you deteriorate is having the right carers and support network.

Having a bad experience with care can make you very wary of new care that’s why it’s essential to get it right.