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 attach document recently used at presentation to health professionals which covers this.*

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

*At point of diagnosis felt bewildered, gobsmacked, confused etc, but still supported by medical profession’s interest after 4 years of diagnostic testing. Their interest whilst striving to identify cause made me feel special, interesting, worthy of investigation. After diagnosis all that interest melts away, you’re left with a vacuum. A name to put to the condition, but no treatment, no cure, no longer of interest. A feeling of being alone, free falling into a big void with no guide, no certainty about what’ll happen when, how or why. Feelings now more stable, but self regulating. It’s down to the individual to gain composure, motivation, self confidence, happiness.*

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?

*Crap! There’s no getting away from it. No escape, no relief or respite. You have to work at keeping positive, being kind to yourself, knowing your own self and asserting yourself in whatever way you can. Difficult enough if you can walk and talk. Magnified hundred times without legs or voice.*

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.

*PBA (pseudobulbar affect) symptoms have caused many ‘emotional incontinence’ sessions. Huge self pitying periods – why me? Triggered by very small negative thing, reaction completely over the top and so difficult to manage. A new drug im trying seems to help.*

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?

*Stay positive. Using techniques from a friend who had ME, but is now recovered, she was treated by neuro at [hospital], I map energy demands so I can maintain energy supplies (everythings worse when I’m tired). I have another friend who’s a hypnotherapist and I’ve had several sessions with her. I’m quite good at putting myself ‘under’, in a trance, using her pathway. I’ve read a lot about mind healing body, so use a ‘mental pathway’ to calm down, get positive, feel whole etc.*

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

*Weekly massage helps. Going to hairdresser, beautician etc, shopping (even on line), seeing friends and family – all important and helpful. Keep doing the things you enjoy, just lower your expectations and standards so you achieve and don’t feel disappointed. Know yourself, recognise your choices and enjoy what you chose. Surround yourself with fun and laughter.*

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?)

*Offered psychologist or drugs. Didn’t need them. Best help is above. [charity organization] very useful and 3 FB specialist groups I belong to all helpful in moderation.*

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?

*Probably could do something , like prompting people towards what might help them. But everyone’s different and needs different help. Look at what the FB groups already provide?*

Hello, my name’s [patient] and I have MND. This is my husband and full time carer, [carer].

*Italicised sections are carer’s experience, can’t use because no consent was obtained. But I have anonymised and left in the document for context.*

*Is the volume OK?*

*We had hoped to use [patient’s] own synthesised voice today; she banked her voice a couple of years ago. But, we’re not yet proficient at using the banked voice for some complex words, so instead, we’re using Google’s best. First tip. If you do work with people living with MND, please encourage them to voice bank as early as possible, well before any slowing or slurring starts, even if it’s just for insurance. The MND Association’s website has good guidance.*

Some MND cases begin with voice loss, excess saliva production, difficulties swallowing, choking, but these bulbar symptoms usually follow after mobility issues. Deep joy!

The disease I have is P.L.S., or Primary Lateral Sclerosis, a rare form of M.N.D., which is itself quite rare. Mercifully P.L.S. is slower than A.L.S., the more usual form. Both are progressive, degenerative neurological conditions for which there’s currently no treatment, let alone a cure.

P.L.S. affects only Upper Motor Neurones. The ones in your brain, with very long axons extending down your spinal column taking signals to your voluntary muscles (or not). No one knows what causes these neurones to pack up early; probably a combination of genetic changes and environmental triggers. Progress is being made in discovering genetic contributions, using the M.N.D. Association’s funding.

I’m not your typical person living with M.N.D. I’ve not got the dreadfully fast rollercoaster whirlwind, mine is in slow motion and may last five or fifteen years. We don’t know.

*The speed of ALS is shocking, with half dying less than two years from diagnosis, many within months. We know some local cases where statutory services failed to provide adequate care because of delays in professional visits, provision and installation of hoists or other equipment. Second tip; diagnosis should automatically start a rapid chain reaction of all the various professionals who need to be involved. There should be red flag status for the required speed to address needs for this group of people and their carers who struggle to cope after such a devastating diagnosis.*

My story starts nine years ago. Aged 54, living in [name of place], working full time as a charity Director, my two daughters were grown and had left home. [Husband] and I had been together for over ten years, having met at Salsa dancing lessons. I’d always been active, enjoying walking holidays, exercise classes, pilates, tennis, skiing and jive dancing.

During aerobics, my left foot wouldn’t tap as fast as I wanted. My G.P. was on the ball and I had the first of many MRI scans at [name of place] very speedily. I was referred to [hospital] and there followed three years of tests, tests and yet more tests, as symptoms gradually worsened. A foot tap, became a limp, I developed spasticity, clonus, muscles getting stiffer and weaker, difficulty controlling movements and lots of falls. The right leg joined in. I took more and more Baclofen, the muscle relaxant, and a drug for bladder urgency. I progressed from occasionally using a walking stick, to using two sticks all the time. During this period we moved to [name of city], changed jobs, working and playing hard, as usual.

[At the hospital] neurologists couldn’t identify the problem, so in September 2014 I went to [bigger neurological hospital], at [name of place], for a week. Usual tests were repeated. By then I was desperate for a diagnosis and at the end of the week, after almost four long years, I got one. But, what you hope for, is a diagnosis that brings treatment possibilities, not one that’s in effect a death sentence albeit with a long time on death row. This lengthy pre-diagnosis period is usual with P.L.S., but frustrating. Diagnosis, which is by elimination, brings some relief, being able to tell people what it’s called, feeling there are others also going through this same hell, and being part of the bigger M.N.D. group brings some benefit.

At [hospital], the [charity organization] fund a Care Centre Co-ordinator who was present when I was told of the diagnosis. She spent time with me afterwards, comforting me, giving me contact details for the [name of area] and importantly telling me about the [charity organization]. Just after diagnosis, [husband] proposed and so 2015 was a brilliant year as we got married in July.

*Yes, 2015 was a special year. But we can’t over emphasise the value of the Care Co-ordinator role. At [name of place] we were under [name of hospital] M.N.D, Care Centre, where the Care Co-ordinator, [name of person], was very helpful. Attending all our consultant appointments, she was easily accessed by email for any little niggles or questions we had. We understand [area where we live] is to have a Care Co-ordinator, which is good news. In [name of place], the NHS Trust also ran our local home care services there, and we were lucky to be linked with a physiotherapist who lived close by. She was brilliant! Probably breaking rules, she kept [patient’s] case file open, and took a special interest in the condition. Linking with [care coordinator] to gain specialist knowledge, she was also easily reached by email, and when we needed help or advice she sometimes called round early on her way to work. We felt really well supported.*

2015 was also the year I had to stop working, taking ill health early retirement in November. My employers had been great, making necessary adaptations and changes, then allowing me to gradually reduce my hours, but they must have been pleased to see me go. I had several serious falls at work and became quite a liability. Whilst still working, I had the advantage of a [insurance] scheme, and accessed regular neuro physiotherapy and hydrotherapy, which helped tremendously with maintaining my mobility, motivation and positivity.

We moved to [name of place] in January 2016, to an accessible bungalow and are now close to many friends and family members. I am so lucky to have two lovely grandchildren, who I see often. Since diagnosis, my arms and hands have become weaker and less controllable – putting on eye makeup is a nightmare; [husband] hasn’t yet mastered eyeliner and mascara. My knitting and sewing is slower, but I still try. Gardening, my passion, is getting more and more dangerous. I have to phone [husband] to rescue me when I topple off my kneeler into a border.

When we moved to [name of place], I was keen to access some physio support. My G.P. referred me to the Integrated Rehab Team and I had a few visits from an OT and Physio. They were clear my case would be closed when the referral reason had been addressed. People with terminal conditions don’t fit this model of a ‘Rehab’ team.

It’s annoying that service access is via the G.P. You hang on a phone line for ages and then struggle to get them to understand. They’re busy, so I rarely ask to see a doctor, using the phone back system instead, but guess what, making myself understood on the phone is a challenge.

For a while I used the excellent private specialist neurophysio services at [name of place], but at £86 per hour, that could not be continued. [names of two people], the respiratory nurses, visit me at home every few months, which is useful. I’ve had great support from Speech and Language here, in the areas of eating, swallowing, choking issues and more lately about voice loss, voice banking and alternative communication tools. I’ve been able to access some good neurophysio sessions at [Hospital], usually when a fall has left me with an injury. Again they’re clear that it’s just a short course of sessions. They introduced me to their weekly gym sessions, where a small group of neuro outpatients with M.S. or strokes used gym machines under the eye of neurophysios. This great facility was closed on my third visit, as part of a cost cutting exercise. We’re able to attend a weekly stretch class at the Westlands centre, and if that becomes too difficult, I can use the G.P. referral scheme to access affordable supported gym sessions. I pay for a weekly deep tissue massage, which helps alleviate some of the painful muscle cramps.

*You’re probably starting to get the idea of just how complex MND is, with the involvement of so many different professionals. Finding a way through the NHS organisations can be a nightmare for carers and families. So another tip is to encourage all those diagnosed with MND, and their carers and families to join the [charity organization]. It offers practical advice, help and information, via the website, helplines and local branches and groups.*

Luckily, we’re financially quite comfortable. Yes, we miss the two salaries we’ve given up to take early retirement, but one of us was in the R.A.F. for millions of years so has a nice little pension! Other families really struggle with the additional costs of this cruel disease.

*From our professional careers, we are both familiar with how to push hard to get what we need and are entitled to, from statutory services. The NHS and DWP both seem to make things as complicated as possible. For some people, the bureaucracy must be daunting, especially when they are on the A.L.S. rollercoaster. The [charity organization] offers help and advice about claiming benefits.*

I’m now under [name of hospital], with twice yearly consultant appointments; mostly I just update them on what’s changed since last time, and they make sympathetic noises. In the past I’ve experienced emotional lability (uncontrollable and often inappropriate crying and/or laughing). Before he moved to Exeter, [name of doctor] prescribed another drug, one licenced for epilepsy, which my Facebook P.L.S. friends applaud. I believe emotional lability is more manageable and bladder urgency reduced with the new drug.

So, what’s life like with P.L.S.? I’m an optimist by nature, my glass is usually half full, but this disease really sucks! Losing mobility gradually was bad enough, not being able to pick up and hug my grandchildren, do any sport or just go for a walk, but losing my voice is much more dreadful. It’s taking away part of my personality. I can no longer express myself properly, can’t read stories to the grandchildren, can’t join in conversations with friends, can’t tell jokes or sing (O.K. I never could do either of those). In my head, I still make quick comments about everything I see and hear, I have silent discussions (pretty boring) and I answer back.

On the positive side, modern developments like voice banking, text to speech software, power wheel chairs, hoists, wash and dry toilets, mobility scooters, rollators or walkers, blue badges, greater accessibility awareness and many other things make life more bearable. It would have been a whole lot worse to have had P.L.S. even 20 years ago. For all its faults, Facebook is a godsend. I belong to three different P.L.S. groups, with membership across the globe. Bringing together people with such rare conditions is useful to compare notes about symptoms, what helps and what doesn’t. But we’re all individuals, with different likes, needs and dislikes. Just having the same disease, doesn’t make us the same. If, in your dealings with people living with M.N.D., you can help them retain some of their own individuality that’d be worth a lot. Spare time if you can, to find out what they want, how they like things done. Remember, just because they’re quiet and still, doesn’t mean the brain is at peace. Mine is going at 90 miles an hour, trying to get out of this rapidly failing body.

*I guess I would like to finish with a look at the achievable outcomes, which [name of patient] just touched on and the conversations I’ve had with other carers. For a long time [patient] was in involved in Barnardos children services and, before retirement, in Guinness Care and Support. For most of my career I was involved in RAF Search and Rescue. These were all hugely rewarding jobs, but only because they were ‘outcome’ driven. Focus could be easily reinforced by the personal stories of people whose lives were made better or saved by the proactive services available. Good news stories! For the last 6 years of my career I undertook the investigation of air accidents; which is quite topical in the news at the moment! It seems to be an unfortunate fact that it takes a ‘catastrophic headline’ before investigations are undertaken and recommendations made to drive corrective action; which often requires funding.*

*However, in many cases the circumstances behind these accidents, or parts of, are already known about and can be avoided. There are many more near events than accidents. It is therefore possible for many small changes to be made at a local level, by suitably empowered and trained people. This can really make a difference, not only in the avoidance of accidents and incidents, but also to make improvements , especially for those in need.*

*For people living with MND and their carer’s, time is not on their side; the outcomes are not good, but they can be improved. [Patient] and I have seen different processes/systems used and rules quoted in differing areas; some are very good and some slow and bureaucratic. In pretty much all areas, the professionals are working there for the rights reasons and doing their very best. We are lucky to have the NHS al all you lovely people.*

*I guess, I am asking that you hard working people look beyond the hurdles in your everyday work to help those in need and push those in management to change the very rules that prevent you from doing what you know to be best practise. With your help and the MNDA campaigning arm of the charity, it may be possible to make life easier for all.*

*Thank you for listening - any questions?*