**Interview 6**

**(person with MND)**

Q1. To start with, can you please tell me a bit about how you've got on with trying the CALM website?

**P:** It's easy to use and visually attractive. Some of the photographs were very nice, especially, for example, the beach scene at the start of the Pleasant Activities section and the woodland at the end of Finding Positives. It's all quite easy to navigate around.

Q.2 Can you tell me a bit about when you generally used the website? How often, what made you log in?

**P:** To be honest, I only logged in, in order to read all the way through it to make a fair assessment and wasn't tempted to return to it for personal use. My approach to having MND is to keep busy; keep mentally active; take each day as it comes and not to worry about what tomorrow may bring. I'm a very practical, self-reliant person and if I had problems, I don't think I'd turn to a website. Sorry.

Q.3 Which section or activities did you mainly try? Why did you decide to choose them? Were there any sections or activities you did not look at? Can you tell me a bit more about why you didn't choose them?

**P:** I looked at every section, but some I didn't linger over. For example, I thought the suggestions in the Pleasant Activities section were banal and not ambitious enough. The first two comments in the Finding Positives section were not relevant as I don't have any family apart from my husband. The

Values and Goals section was a little more interesting, but it's what I do anyway. In the Adjusting to Changes section, the man who gave the instructions for the three minute breathing exercise under Anger had a very dreary voice, so he didn't encourage me to try it. When I came across him again under Frustration, I didn't bother to listen. I think there needs to be some positivity and cheerfulness about the website. We can achieve a calm state of mind through happiness.

Q.4 Can you tell me about whether you had a go at trying out the activities and suggestions from the website? How did that go?

**P:** I don't have unhelpful thoughts because I keep busy all the time, but if I did, I thought the STOP technique under Dealing with Worries and Stress might be useful.

Q.5 Did anything make it easier or more difficult for you to use the website? Could you please tell me a bit about this?

**P:** Under All Activities, I found titles like ‘Compassion Break, Befriending Yourself and Self-Kindness Letter’ very off-putting. I wouldn’t be tempted to look further at these and to be frank, would consider it a waste of my time. I'm sorry to be blunt, but to people of my age (born in the 1950s) these sound very snowflakey. As I said above, more positivity, such as Ann's comment, near the beginning, would help. I found the Other Support section useful, particularly Professional Support.

Q.6 Could you tell me about any part of the website that you had problems with or that didn't seem to work properly?

**P:** There was nothing.

Q.7 What did you think about the Building positivity section? Did you try out any of the activities - Pleasant activities, Finding positives, Values and Goals? Were they relevant to you? Was there anything you liked or disliked? Would you have changed anything?

**P:** I found Ann’s comment helpful because that’s exactly my approach – carry on doing things as normal in as far as you can. I didn’t find Celeste’s comment very positive. Under Finding Positives, I wasn’t sure what I was supposed to be doing in the ‘How to do this?’ section. What does the word ‘experience’ refer to? Is it having MND?

Q.8 What did you think about the Adjusting to changes section? Did you have a look at the activities and suggestions for anger, sadness and frustration? Were they relevant to you? Was there anything you liked or disliked? Would you have changed anything?

**P:** See my comments on page one.

Q.9 What did you think about the Dealing with worries and stress section? Did you have a look at the activities and suggestions for worry and stress? Were they relevant to you? Was there anything you liked or disliked? Would you have changed anything?

**P:** The STOP technique might be helpful under some circumstances.

Q.10 What did you think about the All activities section? Did you try any off the following activities -- Compassion break, befriending yourself, self-kindness letter, 3-minute breathing space, safe place meditation, body scan, pleasant activities, finding positives, values, and goals, and thought distancing. Were they relevant to you? Was there anything you liked or disliked? Would you have changed anything?

**P:** These are not activities I personally would do. I'd rather challenge myself with improving my knowledge of German grammar; doing some historical research; doing a crossword; listening to a comedy or documentary on Radio 4; home improvements; gardening; watching nature; communicating with friends and occasionally watching TV. The above are practical activities from which, with any luck, you can learn something. That's what is important to me.

Q.11 What did you think about the ''Other support'' section? Did the information make sense? Was there anything useful or not useful in this section?

**P:** This was a useful section, but I think you have to be wary of the MND forum. There is a lot of negativity on there.

Q.12 After having gone through the website, how do you now feel about dealing with your emotions? Has anything changed?

**P:** No different. I didn't have any emotional issues before and I don't now. When life deals you a bad hand, you just have to get on with it.

Q.13 Is there any advice or activity from the website that you think you might use, now or in the future? Can you tell a bit more about this?

**P:** Sorry no.

Q.14 How has it been for you using this website during all the restrictions and limitations we've had because of COVID? Were there any activities or suggestions that were difficult to follow?

**P:** I haven't felt at all restricted during COVID. I haven't had to shield; have been out food shopping when I needed to; have met up with friends when it was allowed and have a nice house and garden, so haven't felt claustrophobic. I'm used to my own company, having lived outside my own country for more than half my adult life, often having to manage on my own when my husband was working away. The only changes to my lifestyle caused by COVID have been the lack of travel and theatre trips and that can't be helped.

Q.15 Is there anything else you would like to mention about the website or the activities and suggestions in the website?

**P:** I really do think it needs to be a bit more stimulating and enervating in places.

Follow up question

You mentioned that the kinds of things in the Pleasant activities and Values and Goals section, are things you normally do. Can you give me some examples of how you’ve continued to do this after being diagnosed with MND? Have you had to modify or adapt what you do? And how does doing these activities help you stay positive?

Pleasant Activities

I certainly still spend time outside, both working in the garden and either going for local walks or travelling slightly further afield, according to whatever Covid rules are in place at the moment. We managed two short hotel breaks in this country last autumn and if it weren’t for Covid, we would have been planning our attendance at the Monaco Grand Prix in May and the Catalunya Moto GP at the beginning of June. As it is, we probably won’t be attending any live motor sport this year, but can still follow it on TV. So, with regard to travelling and going out, my plans have been more affected by Covid restrictions than by my diagnosis. The same goes for trips to the theatre and concerts.

I also keep in touch with a lot of friends via email or text and am hoping to catch up with them physically before too long. One disappointment is that I can no longer act as a room guide in the museum where I used to volunteer, so all the knowledge I have is currently going to waste. I asked the Volunteer Manager to find me a non-speaking role when they re-open, but so far, she hasn’t come up with anything and the General Manager’s response when I told her (by email) that I could no longer speak, was not even to reply, just to delete me from the list of volunteers. I only found out when other volunteers started asking whether I’d seen such and such an email and of course I hadn’t received any. I find this attitude disappointing as they bent over backwards to accommodate younger disabled volunteers such as a girl in a wheelchair and a boy with autism.

I have loads of photograph albums from my travels and when we have lived overseas. At the moment, having just moved house, they’re all in boxes in the garage, but I’m looking forward to seeing them again when we’ve somewhere to put them. I usually make online digital albums of our trips and an annual year book, and have them printed, but I’m not sure I’ll bother with a yearbook this year as, so far, there’s nothing to put in it! I enjoy the creativity of making the books though and so will probably do a ‘Before and After’ book of our new home. Using a computer has not so far been affected and another hobby is researching my family tree, which I can still do. I also enjoy doing online history and foreign language courses. I recently completed a course on the Celts with the University of Oxford Department of Continuing Education and am currently doing German for a few minutes every day with Duolingo. Last year I brushed up my Italian with a free course on FutureLearn.

I’m a very creative person and enjoy interior design and garden design. I’ve been decorating – I can still hold a paintbrush - and am currently making some simple curtains, although my weak hands are sometimes a nuisance and slow me down, but I tend to turn it round and be thankful for what I can still do, rather than dwelling on what I can’t. I can still touch type for example, although my handwriting isn’t as neat as it used to be. In terms of things I can and can’t do, I’ve always enjoyed driving. We have two cars and one has a traditional handbrake that I can no longer pull on and off, so I drive the other one, which just has a dashboard lever for a handbrake. I just look for ways round things I can no longer do. The only thing that really adversely affects me is no longer being able to play the piano to the same standard I could previously and that does make me sad. I can’t think of a way round that one.

Values and Goals

I’m a very self-reliant, independent person and I don’t like the ‘one size fits all’ approach from the MND team at my local hospital. They haven’t bothered to find anything out about my husband or me as individuals, but are simply interested in ticking boxes that they’ve informed us about various things. I feel that they are trying to write me off before I’m ready to be written off. I have a very high IQ (1st percentile) and keeping my mind active and engaged is the most important thing for me. I wish the hospital would set me goals and challenges, rather than just being interested in my decline.

I’ve asked my friends in Mensa to monitor my communications and let me know if they think I’m losing it and nobody has commented so far. I’ve written two short pieces for Mensan in-house magazines recently and they were published as normal. And without consciously wishing to be, I think I’m some sort of ‘influencer’ as people often remind me of things I said to them years ago that I’ve forgotten and they’ve remembered and taken on board. I agree with Jo’s philosophy about adapting to what you can do and not stressing about what you can’t. I sometimes get frustrated about having to do things more slowly or when I can’t communicate very easily, but there’s nothing to be achieved by that, so it’s not worth getting upset over. It’s better to look for solutions than concentrate on the problems.

Humour is also important to us, so we listen to the Radio 4 comedy every evening at 6.30 as we have dinner and also for about 20 minutes before we go to sleep each night. I have lots of downloads of old BBC comedies on my iPad. We’ve just finished a series of *I’m Sorry I Haven’t a Clue* and are now listening to *Welcome to our Village, Please Invade Carefully.* Other favourites are *Old Harry’s Game, Radioactive, Round the Horn, I’m Sorry I’ll Read That Again, Elvenquest and The Castle.* There’s plenty of free humour available online nowadays, music for every taste and lots of lectures and documentaries to keep your mind occupied. For me, boredom is the enemy, so my goal is to keep learning new things and not to let my illness put me off.