**Interview 3**

**(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:** Easy to access and follow.

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

**P:** At times alone when feeling lonely, anxious or sad.

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 liked the sections on dealing with stress and anxiety. I chose them as I felt that way at the time. I looked at all sections out of interest.

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 tried the values exercise and enjoyed that. I hadn’t seen that exercise before so was new to me. I liked the concept and made changes to my outlook. I definitely developed from that exercise.

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:** There was a lot of reading. Perhaps some audio especially from the people caring for MND.

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:** Everything worked fine.

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:** As said I enjoyed the values and goals section as that was a new way of thinking to me. Finding positives was relevant to me as it’s important to focus on that particularly at times of crisis. Pleasant activities depends on how far into the MND journey you are. I’d already reached that stage.

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:** Adjusting to change very much needs to be discussed as there are changes all the time. There are new frustrations as a little bit more weakness creeps in. Sadness is an obvious sensation that is going to be felt. There are the five stages of grief that could be used here as it is a loss.

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:** I thought this section lacked depth of real solutions. It acknowledged that there is stress and worry but I’d like the notion on the lines of the reality you can worry as much as you like. Like being on a rocking horse you can go back and forth all day but you still won’t get anywhere.

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:** I loved the values and goals exercise, body scan and safe place meditation. All worthy and not one size fits all so all need to be included to reach everyone and their preferences.

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:** The other support was excellent. Clearly the MNDA is a must for anyone with MND.

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

**P:** Stress is dealt with adequately in the section. I became aware of the benefit of meditation and taking time out to concentrate on me and to be kind to myself.

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:** Perhaps more help for paid and unpaid carers to people with MND. Like carers charities local government support etc.

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:** It was a life line to be honest as gave me something to do and concentrate on. The activities of getting out and doing things that bring you pleasure wasn’t always possible.

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

**P:** Overall very informative

Follow up email:

**I:** Pleasant activities: You mentioned that this was difficult to do based on the stage of MND you are at. Did you feel that this section was upsetting to think about or were the activities too difficult to do? What sort of pleasant activities can you still do? Do you feel activities like this are still useful or relevant, even if you are at a further stage of MND?

**P:** Pleasant activities have severely been curtailed by covid leaving precious little. Stuck in the house with no visitors to help me do pleasant activities made me quite sad and in fact tearful. Carers vary with their willingness to get involved. With family about I think this is more applicable. I did however get some seeds and planted them with the help of a friend outside. That was positive and happened after the feedback was given. I’m still using the techniques. I therefore consider this important and should be included. I am sure it’s very beneficial to those starting out on this journey. On reflection a good friend organised things for me to focus on and we went to France, Theatre, sporting events. etc. In the early days and that was so important and probably helped keep me going during those dark days before acceptance.

**I:** Values and goals activity: You mentioned that you "definitely developed" from trying this activity. Can you tell me a bit more about what you mean by developed? What changed for you?

**P:** I felt much better about myself in that by setting goals and achieving them helped me feel positive. Looking at my values and reassessing where I am at helped a lot. Like I addressed the fact I feel like a burden on the NHS and my friends. I addressed this by asking a close friend for honest feedback. The CHC process each year to get funding doesn’t help but reinforces this thought. I do help others with listening and counselling. Some feel privileged to be able to help someone.