**Interview 15**

**(person living 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:** I am living with MND. I saw the link on MNDA website

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

**P:** I was really interested in looking after my mental and physical health and your site promoted help in these areas.

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:** Thoughts distancing: this was particularly helpful recently as I was spiralling into low form due to a change in my condition where I no longer could eat successfully on my own and my speech had become incomprehensible.

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:** It took me a few times to read about this activity for it to sink in. Nothing to do with the wording but more about me being open to receiving the information. I feel Calm website was tailored made for me at and the timing of being introduced to it was welcomed.

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:** Great support was on hand especially when I forgot password.

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:** (blank)

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:** From this section I began to see that I can see gardening in a different way now. Doing jobs out there that I can fulfil and enjoy. I may not be able to work the way I use to but I will set goals at trying what I’m capable of doing.

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:** Sadness and frustration Mind racing to the future and my adult children not having me to turn to. STOP technique very useful - Making the most of every situation and what I can do right now.

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:** (blank)

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 particularly liked this section. It’s a good foundation for well being and positivity. I found it helped me through a tough time I was having recently when I was introduced to RIG tube feeding and experienced adverse side effects. This section and activities allowed me to look at my thinking “I feel I’m not a strong person to cope with this disease, other people cope” Compassion break: the Audio should be prescribed along side Riluzole (the medication prescribed for MND)

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:** (blank)

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

**P:** In particular this past year has been so difficult for everyone. Shielding was essential but also the consequences on learning to live with MND and newly diagnosed was daunting to say the least. Thankfully I am quite resilient and managed fine but I did hit a brick wall just before I read about Calm. I feel I need to tell you that this programme made me stop and look at what I’m dealing with with compassion for myself and encouraging me to go about my life doing the things that bring me joy and comfort but maybe in some ways a little differently.

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:** I immediately started using breathing into sore and aching areas, mainly my hands. Found this so beneficial. Learning to go at my Own Pace - this quote appealed to me as I had to adjust to a slower moving me because at first I got frustrated and anxious about this change. Calm programme to the rescue once again. Thank you Cathryn and team.

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:** (blank)

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

**P:** (blank)

Follow up question about STOP technique (others asked, but only question about STOP technique was answered):

Stop technique

Recently I found myself overwhelmed with worry and fear of my future living with MND. One year ago I took the advice of my Mnd nurse and had a Rig tube (Mic Key) inserted for use when feeding down the line. In February this year I was forced to give up eating my liquidised and puréed meals. I faced this bravely enough knowing it was the safer option. I struggled finding the correct liquid feed and had to suffer weeks of diarrhoea. I have been very fortunate with this third feed and all is going well. But, I miss eating and it’s something I have to accept and tube feeding takes a lot of time. At this same time in February I came to accept that my mobility is slower and I struggle getting showered and dressed so I applied to have carers come in to help with this daily task. Fear and anxiety took over as I’ve been so independent regarding my daily hygiene and to allow a stranger into my home to help me filled me with dread instead of ease and peace of mind.

With Calm - Stop - I was able to take a look at and acknowledge this worry and fear. See that these new changes will benefit and make things safer and help me. Surely I want the best for myself. Stopping and observing allows a little clarity in the situation and makes for a good outcome.