**Interview 12**

**(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:** I had a look as soon as it was made available to me. Looked at almost all of it, because I had time available. Haven't felt any need to revisit or use it in reality since.

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

**P:** Sorry, didn't feel the need at all. I've always been a glass half full person and I've developed various coping strategies to employ if ever I feel down. Similar to lots of stuff on the website.

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:** As above, sorry. What I can say is that I found the whole site carefully constructed to be welcoming, calming, caring. I can imagine doing any of the activities if ever I had a need, and the time. I am very busy at the moment with gardening, sleeping etc.

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:** Sorry. No.

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:** It was very easy to navigate. Simple but functional. Calming colours, photos, sounds etc.

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:** None at all.

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 already do a lot of this as part of my daily life. As a manager, when I was working for [name of organisation] I supervised social workers, using the Tony Morrison supervisory approach. We did lots of work around goals, values, positive approaches to what was very taxing and difficult work. This has become my way of living. I've also recently done some hypnotherapy with a close friend who is a trained therapist. So I use that approach too.

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 was most relevant, as that is my default position when having trouble with the disease. I liked the gentle approach used. Important to give permission for emotional reactions.

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:** Looked and appreciated. Not relevant as not experiencing these at the moment.

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:** All very good. I do breathing space, finding positives daily. Great believer in self compassion. Practice it as much as possible.

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:** Yes. All useful stuff.

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

**P:** Felt reaffirmed. Good to be reminded of what helps get one through. Feel stronger, less alone, a good resource to know its all there in one place.

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:** Probably keep doing my own '3 or more good things that happened today', and my complicated, much embellished but ingrained into my memory, 'route towards relaxation' which puts me into a trance like state. Used it at the dentist this week, so didn't need anaesthetic.

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:** No

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

**P:** Thought it might be useful to change things occasionally to keep it always looking fresh, But need to retain structure for familiarity. Maybe swop a picture sometimes, add resources, so it doesn't get boring, yet users can still find what they need easily.

1. You mentioned you use approaches like values and goals already and are familiar with them. I wondered if you had an MND specific example to share? Or something about how you’ve applied this approach to a problem you’ve encountered since having MND?

I think it helps to recognise what's important to you. What you value and why. What makes you happy. I believe happiness comes from within. It's yours to control. You can look at the world through rose coloured spectacles if it helps you to get through the hard stuff. I focus on what is possible to control and change. Don't bother about stuff you can't change. Let it go. Sometimes that's a challenge. I used to be a real control freak, but I've had to adapt and look at things differently. I've always believed you should aim low and then over achieve. If goals are set too high you risk disappointment or even failure. Be realistic and aim for what you really believe is achievable, given reduced circumstances. Maybe count in a few unforeseen incidents in the planning and then celebrate the goals achieved however small. Be kind to yourself. Reward the achievements.

One of my values is around a love of outdoors and nature. It's one of your examples on the website too. I used to be a keen walker, long distance, mountains etc. Obviously this is no longer possible and at first that made me turn my back on everything to do with walks. But.... Now I like to look at photos of when we were walking, watch TV programmes of long distance walks, hear from my husband about his walks, visit [name of county] where we used to live and walk and even take my scooter on parts of the coastal path where that's possible. I've an ambition to take the train up Snowdon and a gondola up the Alps, when Covid is over.

I've always been a keen gardener and I still get great pleasure from being out there doing what I can. I could think of all the gardening tasks that are now beyond me, but that'd be a very black and miserable place. My daily list of good things will usually include sun or rain, both are good for the garden, hearing a bird song, seeing a favourite species, reading a gardening book or magazine, watching a TV programme, finding a seed has germinated, or just breathing in that fresh air. Celebrate by pausing, allowing yourself to relax and enjoy whatever you can see, hear, smell or taste. Be kind to yourself. Register the pleasure. Let the rest go. Let it go.

2.       Sadness was a relevant emotion for you. In the website, I had suggested the activity of ‘thought distancing’ where essentially you take a step back from unhelpful thoughts and then get some perspective. I was wondering if you tried this activity and what you thought of it? If you felt this kind of activity isn’t for you, are there any other things you do to cope with feeling sad?

Yes I do this stuff. When my first marriage broke up, I was able to access therapy through my workplace. It worked well. I learnt how to acknowledge feelings and put up protective barriers to stop getting hurt more. I developed a thought pathway to help channel my thoughts in a useful way. I used this to calm down, to be able to face challenges etc. Mine involved a beautiful Faberge egg, with intricate carving and decorations, carefully wrapped in cotton wool, then a purple velvet cloak, then wrapped in a stronger fabric layer of denim, and finally protected in a strong metal cage padlocked shut.

I like the thought distancing approach. It can become an automatic, quick response so eventually you stop having the negative thoughts at all. With MND it's easy to get fixated on how your body is failing as the disease progresses. But instead I look for the smallest possible improvements, or just celebrate what I can still do. Ignore that it's less than before. It's still something.