**Interview 13**

**(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:** To be honest I didn't find any of it helpful - sorry. A lot depends on what stage you are with the illness but more importantly what your lifestyle has been like prior to getting the illness. The further on you are the less helpful it is to be told to have a coffee or chat with friends when you can't speak or drink or eat. Also to be told to go for a walk when you can't walk is pretty useless. In addition, if you have been a keen gardener to be told to get in touch with nature is saying the obvious. So I found it all a bit condescending and of little use. More to follow below.

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

**P:** I used it when you first sent it. I quickly went through it. then I looked at it again a week or so later to check my initial thoughts were right and made a few notes for this survey. Other than that never used it.

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 all. None were of interest to me and I didn't try any.

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:** As above - didn't try any.

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:** I was able to use the site easily.

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

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:** Sorry i thought all those things were either obvious or of little use. I was very positive to begin with and did all those things apart from meditation - I am not into that. As time has gone on positivity is hard and I am now at the stage where all I want is to die as I can do so little. I long for a chest infection or pneumonia. As I said above it's little use to be told to have a coffee when you can't!

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:** I'm not into three minutes breathing space! Not for me. As to getting fresh air or listening to music - sorry you are stating the obvious. It's what I do everyday! I have a lovely garden so I'm lucky - I spend hours either sitting in it watching nature if warm enough or sitting by a window doing the same. I don't need a website to tell me that!

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:** First I have no worries about fast heart beat or other symptoms! I have atrial fibrillation so get fast heart beats and hope it gets worse. As for practical tips - you are stating the obvious. One of the first things I did was to sort out all finances transferring everything to my wife. I spend all my time dealing with extra aids - my wrap around team is excellent especially my O.T. who provides everything I need. Care is sorted as is end of life with my G.P. and the hospice.

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:** Not my cup of tea!!!

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:** I knew about all those and visited all those sites a lot in the early stages when I needed answers to how my illness was going to progress. All very useful. The MND association has been very helpful. The lead nurse in [name of place] answered many of my questions. Those sites would be helpful to people if they weren't familiar with accessing things on the internet.

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

**P:** I'm afraid the website activities and suggestions annoyed me as I found them obvious

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:** No. I have had no worries about Covid. It has not limited things. I have been able to see family carefully.

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

**P:** Think I have said enough!

Follow up:

**I:** Thank you for taking part in the study and for your honest feedback. The website has had some mixed reviews, and I agree with you a lot of the suggestions are probably more suitable for people at earlier stages. I’m sorry the website was not helpful for you, I would like to improve this because I know there will be other people in a similar situation and I would like to make it relevant for people at all stages. Your feedback has been really useful and I will make changes accordingly.

I would just like to ask you one more question if you don’t mind. Before you had a look at the website, what sort of help or support did you hope to find? Were there any concerns/things you were struggling with that you hoped the website would have information about?

**P:**

Hello.

In all honesty another source of information isn't really needed to address concerns/worries. The MND Association website tells you everything you need to know and the wrap around care from the NHS gives you a lot of support. I personally accepted the diagnosis from the beginning.  I made the most of the time I was active, and as a very active person to be now faced with paralysis is horrible, but I accept that's my lot and just want to die as quickly as possible. Positive thoughts are easy when you can do things for yourself, but hard when you can't.  I don't think anyone or any website can help.

Sorry I can't be of more help.  I hope some sufferers find your work helpful