

A wonderful lady on Brain Fog

Q: What does brain fog mean to you?

It means that I forgot to do different things, I've forgotten where something is and drive myself mad trying to find something - that what it means to me, really. And it can be sort of tiresome on occasions and frustrating but that's, I kind of got used to it by now.

Q: Can you give me an example or some examples?

I kind of have to check my diary, not just once a day but a few times a day to see what I'm doing the following day because I've forgotten, you know, I'd actually forgotten. And there is another thing that really annoys me, that I am trying to find something, say my mobile or something and I'm running from room to room to find it and in the end it is where it was in the first place but I couldn't see it. It's very odd, I know, but that's... it's a bit frustrating as I say but I'm learning to cope with it.

Q: How did you come across brain fog? How did you identify brain fog in your life? How long has it been going on?

Well, I think it's been going on for, I would say, over two years and I think it started when I started having chemo intravenously. Nobody ever told me about brain fog but I read about it in a Macmillan book or something but no, my oncologist or anyone at the hospital has never told me about it. So, I had to try and deal with it myself and because I had read about it I thought, well, yes, this is what is happening with me.

Q: Is brain fog different to being tired and exhausted?

Not necessarily, but then I haven't put it down to being tired. It's more an ongoing thing, I never put it down to being tired or having a bad day or so.

So, nobody from the hospital has ever talked to you about brain fog, that you might experience that?

No, never, it has never been mentioned. You know, I've talked to others, like chatterbox and other people and they would say, yes, they have similar brain fog.

Q: It seems that nobody really seems to know what brain fog actually is and what it entails.

That's right. No, except WE know because we forget and that's how I sort of analysed it, this brain fog. But other than that, what do we know?

Q: Do you have any tips on how to deal with brain fog or how to cope with it better? For example, somebody said that they made a spread sheet where they put in when to change the bed linen, when to pay the rent and so on.

No, I don't think it's come to that for me. You know, I really just get on with it. It's part of me now. I do what I have to do or don't do what I should do (laughs)

Q: Can you give me an example of something that you don't do that you should do?

Like last Friday I know I should have changed my bed linen. I didn't do it. So, I think, in the end it was Sunday before I did it. It's things like that. I know, they need to be done but I think, oh, well, I'll do it tomorrow or it can wait.

And I was never like that, never! And this is what I'm sometimes sort of disappointed in myself because I was always on top of everything, you know. And that doesn't seem to be the case now.

Q: So, do you feel like you lost control somewhat?

Yes, I suppose you could say that. Yes, you could say that I don't care, or don't care anymore whether I change the bed linen or whatever else. It's almost like, do I really care? You know, I'm not well, it's about ME - sod the bedlinen, sod everything else. Yes, that's how I feel now. I never, ever was like that! I was always on top of everything. Always! A real sort of perfectionist if anything but that's not ME now.

Q: So, has there been a shift in your priorities, maybe?

Yes, yes, I would say so.

Q: How to distinguish between brain fog and 'normal' ageing?

Yes, well, I'm not sure on that one. How do you distinguish as to which is which, really?

None of the doctors at the hospital has said that to me when I have forgotten something, none of them has ever said that that could be because of your age.

It would have been nice if they had told us or me about brain fog because you would have been prepared for when it happened. You would think, oh, well, yes, I have been told about this.

Q: Instead of maybe thinking there is something wrong with me?

Yes, yes, of course. It's like 'Am I losing the plot?'

Q: It does sound very scary. Maybe if you know about it it would bring down the panic a bit?

It does, it does. It sort of overwhelms you sometimes, you know, thinking that 'I am losing the plot'. And I am NOT losing the plot! (laughs)

But, you know, in all of it you can see, there is a funny side to it as well. You can get cross with yourself or you laugh because you've done something stupid or you haven't done something. All in all, you have to ask yourself, is it so awful, whatever it is. Is it brain fog or.. You have to see the funny side of it.

Q: Have you been taking a variety of drugs and if so, does the brain fog vary from drug to drug?

Well, I can't really say that it affects me differently but of course I've been on chemo, two lots of it now over the past few years, different medication but I've never actually thought 'Oh, I'm worse because now I have changed my medication to whatever'. No, I never thought like that.

Q: You probably would have noticed a change, wouldn't you?

I think so. If it was worse, I would think so.

Q: Is there anything else you would like to say?

Well, as I say, I just accept it and get on with it and do the best I can with it. And, you know, I am sure it's not just cancer patients, it affects a lot of people for different reasons. So, I mean, it's not the end of the world, I think, that I have brain fog. As I say, I see it sometimes as it being a funny thing and sometimes I get cross - so what?!

THANK YOU FOR SHARING YOUR EXPERIENCE!