I know what I like

Lovely mug ugly mug

BJF
Beth Johnson

Lovely mug

I don't have a favourite as such, but I belong to a organisation in Stoke-on-Trent where we have a peer support group. I am the founder a member of that. I actually started all this for people living with dementia in that group. Somebody who's got a connection with dementia. We don't have carers, we only have people who have actually been diagnosed. There are times when I actually chair it and you know we've done quite a lot within the group.

That organization is called BJF. It's Beth Johnson Foundation in Stoke-on-Trent. It's part of the DEEP group. It's an organisation. They act as advocates for people with dementia. I have been with them now over 12 years. I was diagnosed in 2010, and ever since then I've been part of this Beth Johnson Foundation. So on every zoom session I use this. So it's my favourite.

Ugly Mug

The only thing I don't like on some of the mugs that you have is the clear glass ones where you can see the tea? I can't deal with that if can see it. I am alright with juice but tea or coffee, I just need to see the top of it not the whole lot.

I've been in some cafeterias where we have sat and had a cup of coffee or tea or whatever, and they've given us these clear cups and saucers. They look nice, but I think it's probably alright for milk but not for tea.

As a child, I used to have a favourite glass. Nobody else could use that. It was mine, until about 7 years of age. I remember that quite clearly. It was mine. It was bought for me and nobody else used it. It was one of these clear glass-es once again with a fancy sort of handle on it.

Colour

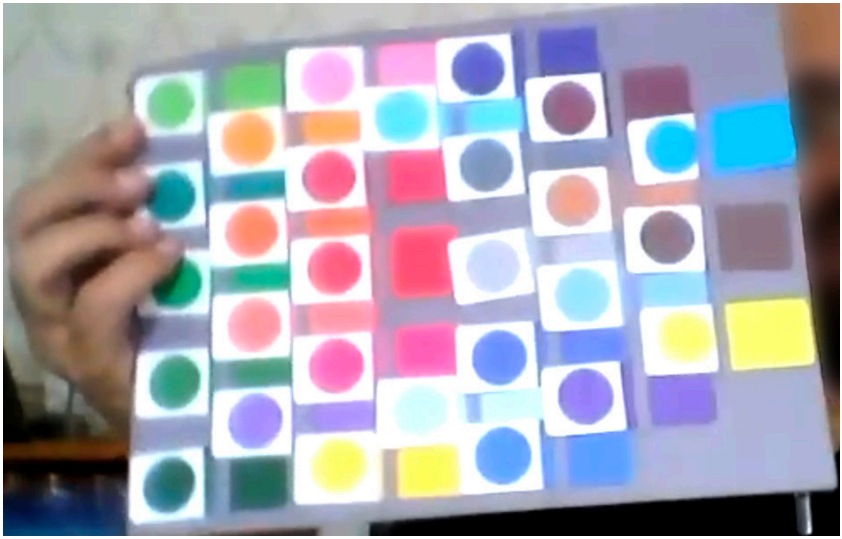
My Senses

I feel that my senses, the 5 senses that we have, I feel that they are magnified. I don't know whether it's because I'm concentrating more?

You know, because I know that deep down back in my head I know I've got diagnosis of an illness, and I need to concentrate a lot more than a normal and I need to pay attention to all those things. All you know is it's progressive, and you don't know when that change is going to take place and that concern is always there with you.

Maybe it's that concern that makes you a bit more aware of what you're looking at and what you're listening to it, who you're talking to, and therefore you concentrate more. I'm mature enough to understand that, and accept the fact that there is nothing one can do about it and I think the thought of having that has made me more aware of things. So maybe its the reason why it's happening.

But I can see better, I hear more. You know, I feel more, I sense in every way more. So all the senses have sort of got magnified So therefore all these things have become extra sensitive, and have increased in a manner that is positive for me.



How do you find the arrangement of the colours?

I have no problems with colours at all. I mean, you could have these. These are a fairly big size. If they were smaller I might find them a bit overwhelming or confusing.I know people who are experiencing this, but I personally don't have any problems.

This size and bigger than that, even the size of the cardboard itself wouldn't make any difference to me. It's just like the rug that I've got on the floor. It's got so many different colours, and I can see every one of them. It doesn't give me any problem.

There is no such thing as a dull colour to me. I haven't got a problem with any of the colours. None of them bother me. I can see colours fine. I can relate to them. I don't think there are any that I don't like as such. But if anything's too bright which could be my favourite colour as well, I dont feel so comfortable with.

I know what I like

Something like that which is too bright, I'm not too keen on.

But when I said that I had just had my cataracts done, because the colours were too bright.

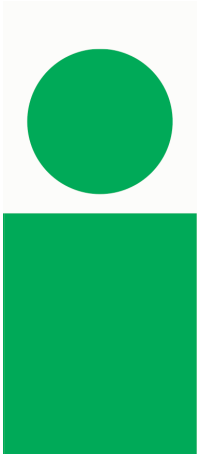
But when it's got writing on, the writing is visible. When I look at that, I don't see the yellow paper I see the writing on it because you concentrate on that.

https://madainproject.com/green_dome

This green. This is associated or it's got a link with the faith. It has a religious meaning to me this has. Because the Dome in Medina, the Prophet's Mosque is green, and because of that, a dark green colour has a significant part in my life. It's a personal thing. I would think that I am not pure enough to wear that. I'm not good enough to associate myself with that. I have a scarf or a hat in green. I've done that, but not clothes, out of respect.

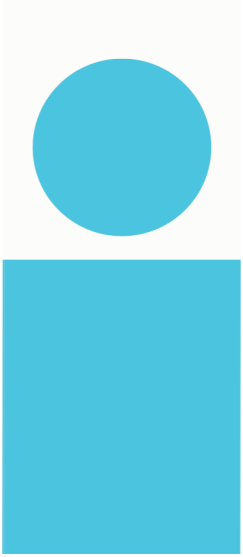
I have been several times. Five times in total. Cherished memories, because it's a holy place. When somebody like me ends up at a place like that, it's a blessing. I haven't got the words to explain the feeling that you have. It's overwhelming.

You're only allowed to spend one month because of the restrictions, because there are that many people going. You're busy. Time flies because you're going from place to place, and you're sightseeing. Because with the faith, you go everywhere the Prophet has been, or try to go as much as possible to see the places that he saw. There's a lot of history there, and it's time consuming. It's tiring. It's demanding.



Then if you go to the slightly less green, that is also a sort of highlight in the sense that everything is OK.

All systems go.

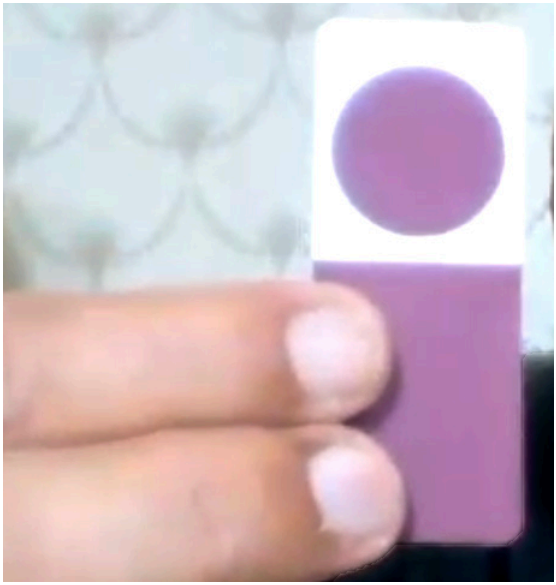


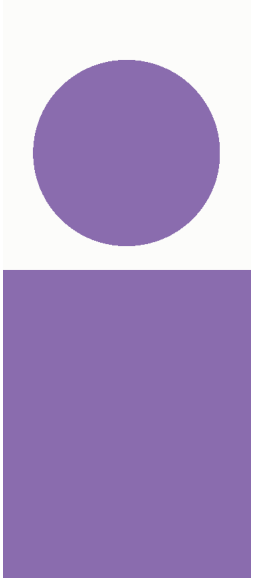
I like blue as well. This blue.

Supposing if a room was decorated with that blue colour, that would be more appealing to me. It's pleasing to the eye this is.

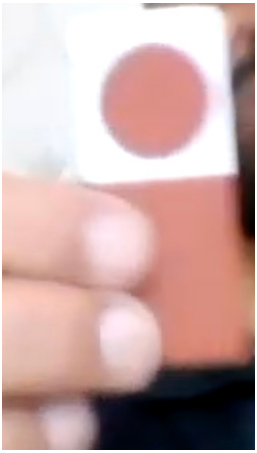
I have worn that colour.

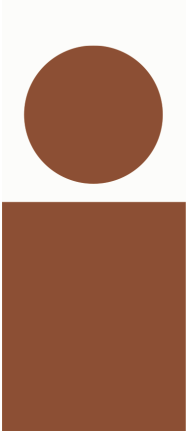
I would prefer that, or even this one, which is slightly lighter.

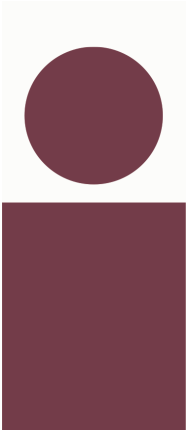


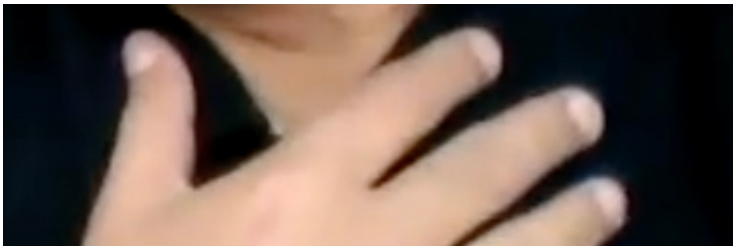


As opposed to that colour.





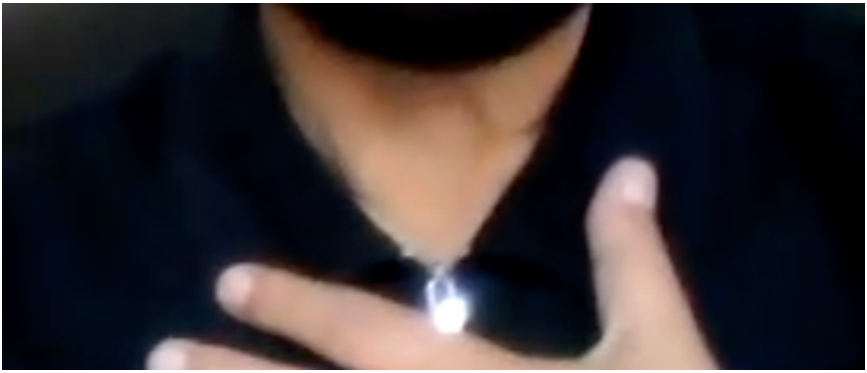




I have worn this colour as well

and this one

I have got black on now



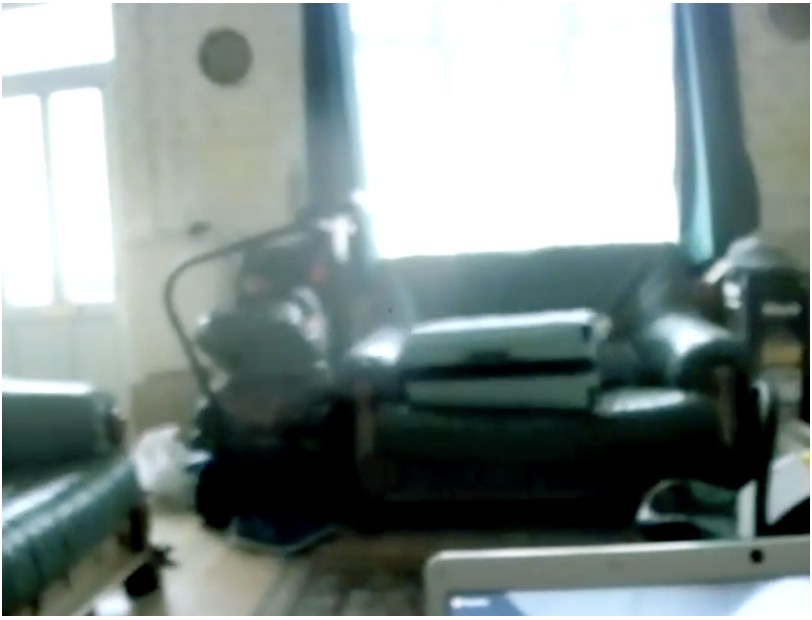
My appearance is my identity and it's important.

I think the type of industry you have worked in, the atmosphere or the surroundings that you have lived in, the type of education you had and maybe the type of people that you associated with all has a bearing on dementia pathways.

There are people out there that say: "*You don't look like you've got dementia?*". And they've gone a lot further than that, and said: " *You don't dress like you've got dementia?*"

I haven't had that the experience. But I know people who have. I think these heightened senses, if you like, have made me so aware. I know this is the only bit you see on Zoom, but I make sure that I'm at least presentable. Pleasing, if you know what I mean. Like today, this is my second meeting and I've got 2 more meetings to go, and I shan't be moving out of this chair for another two and a half hours. I'm meeting different people on every single one. But if in one of the sessions I was meeting the same person, then I would probably change my T-shirt. For two reasons. One is that these people have seen me like this now, and secondly, I want these people to realise that I am conscious about how I look.

Personal space



I've got sort of a green theme if you like:

Green sofa -(my sister is going abroad and she's asked me to borrow a suitcase so I've got that ready for her!) And then the curtains.

I don't know if the wallpaper is visible. Can you see the little bit of green in there?

And then of course the rug

My house is like a library

And then the contrast with the books I've got all colours.

I was a reader, a writer, a translater. I speak 14 different dialects and languages. I can write quite a few of them. I can write from right to left to right.

Being bilingual, while we are talking, I might be thinking in a different language, and then I have to translate that into the language that I'm speaking in and that is my name in another language.

I'm afraid this is the bit that the dementia has taken away from me. Where, you know, I used to write and read and translate and do quite a lot, and I've lost some of it . But I've still got the books, and now I have to refer to them every time whereas before I could remember.

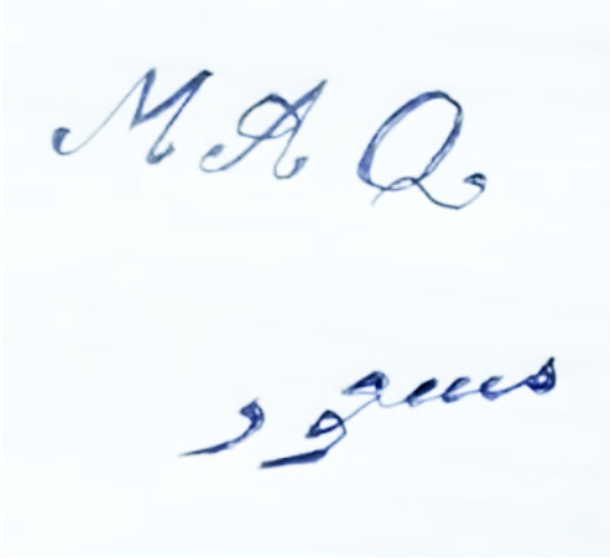
My Globes

You've got loads of colours on there, and I can see them all properly, and the same on that one but . You see, the background on this one is paler

The colours on the globes I can see them all and you know, with this one you've got white marble?

Some of the colours on here are shellfish and every single one of these globes apparently, is handmade. When you get when you get one, it might not have the same colours. For instance, Australia might not have the same colours as on the other globe.

They're all handmade, and they're costly. There are stones and it says in the book some are shellfish and some are other types of fish.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I'm a calligrapher. It was a hobby I enjoyed.

Some of that has been taken away by this, and that in itself, upsets a person. You've lost some of the abilities that you had before. I don't know whether it's the disease that's done it, or the thought of having a disease that could do it, has done it? I think my concentration went elsewhere, you know, with this condition, Isort of put it out of my mind: thinking I won't need this skill anymore and it won't be any good.

So I lost touch, and hence that practice wasn't there, you know. So I just kind of stopped, without even realising it. There are rules to calligraphy, I have forgotten some of them. It is an art, there's no two ways about it.

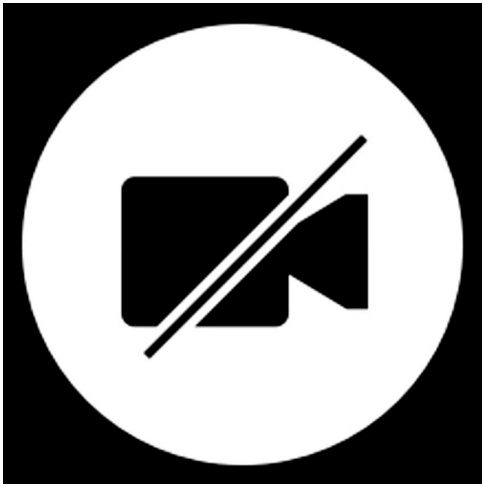
Some of the languages you have to write from right to left, and I used to do that pretty well. I can still do it, but it takes me a lot longer. I haven't lost the skill of doing it , it just takes me a bit longer. There are special tools for that, yeah. Paper is fine, I can use anything. I can even do it with a pencil. It is a bit like drawing. I have never been able to draw anything! But writing wise, I just didn't have any problems.

I feel comfortable here, because, in my 'sane life' I used to spend a lot of time here.

All the books that I have I don't have to look. I can just go like this and pick out the one I want, because I know where everything is, you know.

Like I when I was in the office and working over here, I didn't have to look, I knew where my red pen was when I need the red one, and the blue one and the black one. You know, as you do. It comes second nature, you know. It's like driving the car, you know exactly where everything is.

So that way you get attached to that particular place. And I've had this (chair) .. with me for about 15/20 years. It's one of those chairs that you press a button and it massages you It has paid for itself God knows how many times over .Good investment! I feel that, you know, you don't have to have an illness or a condition. You need your own personal private zone, if you like, and this is what it is.



I can talk to you, I can do whatever it is that I want. It's my own place, and if the worst comes to worst I can just do that. and then you can't see me.

I think this is where the professionals need education because they don't fully understand.

There are times when somebody with a diagnosis, might not be able to express what his feelings are, but it doesn't mean that he's not feeling them, or he's sensing them, you know?

And that is hard for the person with the condition to explain. I don't think that the professionals are skilled enough to be able to see that. They dont look at the person

About me: how I was diagnosed

I think it will give you an idea of where I am coming from and how it all happened. I had major heart surgery in 2009. It was a triple bypass. I was in hospital for 22 days. It was a 12 hour operation, and I came round after 21 hours.

So it was a terrible thing. Apparently when they do surgery of that nature they do a brain scan as well, after the surgery. In those days they did anyway. So I was out of it. I didn't know about the scan and apparently it was that scan that showed up my FTD. So in a sense I found out about it before my GP did because I had a visit from the consultant at home. Back in the good old days they used to come to your home to see you. You didn't have to go to see them.

So the consultant from there sent a representative from the hospital and she came and it was at home that I was told that, we have done something to this: your heart is working fine, but its your brain. So you can imagine what I went through because I was recovering already. I refused to accept it. I just couldn't accept the fact that there was something wrong. Because I had no symptoms. None whatsoever.

So it took quite some time. In fact, I went into a lockdown situation. For 12 months or so I couldn't face anybody. Two main reasons for that: one was that I did not know much about the disease and the other one was that what little bit I knew was that it was the worst possible condition one can be in. And that was frightening.

That's where the perception out there needs to be changed. I mean from 2010 to 2023. It's a long time.

I was a professional. I was an accountant. In the days when I did book keeping and accountancy we didn't have computers. It was a calculator, a pen, and lots of (brain work). It was time consuming and very hard work. Whereas now you just put the figures in, and it does the job for you. So it was tough. And being a professional and not feeling that I'd got any sort of problems anywhere. It hit me. I think the thought of having a diagnosis, that to date is not curable, did more damage than the disease itself. So it was a difficult couple of years.

Being an activist

I I've been an activist ever since. I volunteer for Alzheimer's Society and I belong to eleven different other organisations inked with dementia. I've hosted so many webinars on different topics. I've spoken to over 3,000 people in the last 3 or 4 years through Zoom, or Teams or whatever. I've met a lot of people and the majority of them are still of the same opinion: that there's no follow up.

What motivates me is the fact that I don't know how long I will have the ability to do what I'm doing now. So I want to do everything yesterday! I might not see the result of this, whatever it is that we do, but we've got a goal. We're trying to do something for the cause. That's the top and bottom of it. I might not see the results but my grandkids might, and in a sense I feel that it's a legacy. I have done my best to say yes to everything, and to do the best I can.

Having said that, it's not easy you know. It's demanding. You have to concentrate and you have to be professional.

The disease itself, there are certain sort of side effects of the disease, whereby you might say things out of place or something. Use bad language or whatever, without knowing. We have to really concentrate and then be professional and talk to whoever it is at that same level.

Yesterday at at Northampton University, it was all memory when they talked about dementia. Memory, memory, memory, memory, memory, and you've got memory clinic. You've got this for memory and that for memory.

And I said to them, I said memory is the least of my problems. I'm not saying that I don't have problems with memory, I do. The questions they were bombarding me with. and the answers they were getting. They couldn't believe that somebody with dementia who's been living with a diagnosis since 2010, and answering their questions and asking them questions and putting them in their place as it were. They couldn't believe it.

Just before I finished, I said, memory is the least of my problems, But I've forgotten what my other problems are!

The professionals need educating

There's a thing with bilingual people. People that speak more than one language. What happens is that they sometimes think in a different language. I think in so many different languages. When you think in a different language, and then you translate it back into the language that you're actually using at the moment, that takes a little bit of time. And that time lapse sometimes is misunderstood by the professionals. They assume that it's a speech defect, or something wrong somewhere.

So consequently he or she is deprived of the treatment that he or she would get because of that reason, because of that misunderstanding and that perception. So all these things need to be changed and need to be looked at.

Everybody says that if you have met one person with dementia, you have met one person with dementia but the professionals don't practice it. If you've met anybody who's mentioned memory clinic and the tests they have to go through. I believe they are degrading. It's a humiliation that you go through.

For instance, my consultant, says to me: "*Can you write something on this piece of paper?* " and he handed me a pen and paper and I wrote "something" and gave it him back. I said: "*Here you are. You asked me to write something and here is something !*" Then I grabbed the paper back and I wrote: "*What else would you like me to write?* ". Because I felt that it was so insulting.

I said :" *I'm a professional. You're a professional and let's be professional about it. I know I've got something wrong up there. I know it's not working to its fullest but I haven't lost all my marbles. I am still me and I am still capable of doing 99% of the things that I used to do.*" I said to him: "*There are some things that I can do better than yourself because that was my field. You can't do balance sheet. You can't do tax certificates, I can.*"

The only way changes will take place is when they talk to people who are actually living with it. Get people involved and not just just hear them. Listen to them.

I've realised that people living with dementia connect better with people living with dementia.