

Dear Marilyn,

I see that you have had your diagnosis of dementia confirmed. I am sure you weren't surprised by this. I expect you rushed headlong to the library to read up on dementia to find out what lies ahead for you, I know I did.

I have learned a lot about dementia post-diagnosis. When I read that life expectancy for someone with Alzheimer's was around 7 or 8 years, I must admit that I worried about my mortality! No wonder we were all encouraged to write a will and take out Lasting Power of Attorney! However, we can still make choices. You can sit around and mope, doing the 'poor me' thing, or you can get out there and do some living whilst you still can.

Friends are important at times like this and you will quickly realise who your true friends are. What I call 'fair weather friends' quietly removed themselves from my circle. It felt like they thought they couldn't handle a terminal illness. Did they think my dementia diagnosis was catching? Just like those diagnosed with cancer, some people cannot look beyond the diagnosis to see the real person. Someone who was the same person as the day before she was diagnosed.

You must keep busy! It is easy to sit around watching daytime television. You will quickly find a cloak of apathy envelop you if you go down that route. I joined a gym quite quickly as I realised my balance was rather dodgy. Instead of keeping quiet about my diagnosis I let everyone know of it.

I think this was a good thing as it started up the usual response: 'You can't possibly have dementia, you communicate so well!' My stock reply was that I have the certificate to prove it.

I had such fun at the gym. I could walk there easily from my flat. I was there as soon as the doors opened. It was something to get up for. Of course, exercise is very important, gets the endorphins going! I made some good friends there until the pandemic, when everything shut down. Having nowhere to go and no one to visit was pretty bad. I couldn't go to my choirs and had no family close by to join their bubble. It was then that I joined online groups. There was an online choir I joined. My Alzheimer's support worker phoned me and told me about an online group called Dementia Voice that I could join. I did. I am still involved post-Lockdown and have made more likeminded friends. I have joined so many groups aligned to dementia through this society and Age UK.

I know you are already in receipt of PIP because of your arthritis. Don't rush to inform the DWP of a change of circumstances, like I did. When I let them know, they cancelled my PIP altogether and it took me 12 months to take it to appeal to get it reinstated. Morons! You will quickly realise that everything to do with the DWP will involve a fight to get what you are entitled to.

Did you know that you are entitled to exemption from Council Tax with this diagnosis? It wasn't until I moved from North Devon to Worcester to be nearer to Rachel that I was successful in getting this as your GP has to confirm your

diagnosis and mine had not realised the importance of the council's request. It was only when my Rachel sent a copy of my diagnosis letter to Worcester Council Tax department that I was granted this. What a saving. Even better, they don't ask for confirmation that you still have dementia!

One important thing I have learned since my diagnosis is to try and pace myself. I have a tendency to say yes to everything asked of me and this can lead to more brain fog than usual. A good diet is also vital to keep you physically on top form. It is too easy to slip into a routine of grabbing a sandwich rather than having a cooked meal. Do you find you forget you have started cooking and move away from the kitchen until the smell of a pan boiling dry draws you back in? It has taken me a few years to remedy this. Recently I had pneumonia which meant a fortnight in hospital. After discharge, my daughter sourced a local cook who makes the most wonderful meals that I can freeze and use when I need to. Job done! Don't need to use anything except a microwave now... as long as I remember to take the food out of the freezer the night before! Talking of remembering, I strongly recommend using Alexa to remind yourself to do things domestic, like fetching your laundry from the laundry room, taking your medication etc.

One thing I have learned from all this dementia lark is that I am the expert. I live with it and know much more about both it and me than I ever did before my diagnosis.

I am sure you, with your positive mental attitude, will overcome what problems you incur on your journey. Always remember to ask for help when you need it. There are a lot of really good people out there only too willing to assist. Talking of the term 'assist', did you know that travelling by train is not insurmountable if you use Passenger Assistance? It can be booked on the phone or online. I always use it now and have found it most helpful.

I could write much more about this subject but I don't want to spoil your fun in finding some things out for yourself, so will leave you to read this homily.

Bye for now, see you on the other side... wherever that is!!

Marilyn