

What is it like living with MND?

I have knowingly lived with MND since 14th February 2022, but my first symptoms appeared on 28th December 2020 when I suddenly found I could no longer lift my left foot and my left foot started to slap the floor as I walked (Drop foot).

I am now 64 years of age, so was 62 at the time and I regularly did 30 minute sessions on the exercise bike along with walks of up to 5 miles with my wife. From March to October we would go for bike rides usually for about 20 miles, but every now and again we would do a 40 mile ride. At the time we were living in Lichfield, so we did not have the flat countryside we have here. My wife and I would walk the mile into town to do the shopping rather than use the car. Until our move to Lincolnshire, I worked as an exam invigilator at a school in Lichfield and it was just under 1 1/2 miles each way to school, which I walked or cycled instead of using a car.

For nine years after retirement I had an allotment where I used to do a lot of digging and grew my own fruit and veg. That plot was 2 miles from home and unless I was taking heavy stuff to or from the allotment I would generally walk there and back as I used to take my dogs 'Rosie' and 'Gordon' with me.

By retirement, I mean I left my main place of employment but continued working to give me something to do and to earn pin money.

Now, I cannot walk unaided and no more than about 50 yards without both sticks and a leg brace on my left leg to hold my foot up and to stop my left knee giving way.

Due to covid-19 I was unable to see a doctor until May 2021 and it was thought I had 'drop foot' caused by a trapped nerve in my lower back. I had a number of MRI and CT scans but apart from age related deterioration in my discs, nothing was found.

It was then thought I had a trapped nerve in the back of my left knee and had further scans, long with spinal and brain scans.

On 14th February 2020, I went with my wife to see the consultant neurologist who dropped the bomb shell that she was diagnosing me with MND happy Valentines Day. We both thought I was going to see the neurologist to find out how they were going to deal with the trapped nerve.

At first I was able to continue with my exercises, stretches and normal activities, hoping everything would come good in the end. Slowly though, I have noticed severe muscle loss in my left leg and problems down my right arm and hand.

I am left handed, so the loss of grip in my right hand was not a massive issue, more of an inconvenience. Sadly, I have now lost a lot of strength in my left hand and can no longer grip very well.

So, what has changed in reality....

We have had to move into a bungalow as stairs are too difficult. Over Christmas we stopped with relatives in their house and I really struggled even with physical help from Angie, trying to get up and down stairs. Indeed there were nights when I simply had to sleep in the armchair as I could not face the prospect or the pain/tiredness of trying to get upstairs.

I used to do a lot of DIY and would change light fittings and do a lot of photography. I now have to get tradesmen in and I can no longer hold a camera properly.

We would walk long distances to catch the sunset or walk in the hills to get beautiful landscapes. We would scramble over the rocks at the seaside to go rock pooling. We would take our cameras with us on our bikes so we could travel quietly in the hope of seeing a bird of prey or deer.

Over the years I have enjoyed making small model kits and one of my sons bought me a kit for Christmas. I tried to do it last week but could not grip the small parts and was unable to apply any pressure to push the parts together. I ended up breaking 2 of the parts I tried again a week later while my wife was at work but still could not do it.

I cannot stand the cold. I used to be able to walk round in 't-shirt' all year round and it was always me moaning about the heating being on in the house during the winter. Now my joints and limbs ache whenever the temperature gets below about 6 C.

The hardest part is watching how this is destroying my wife's life. We used to go everywhere and do everything. Now she has had to join a walking group and go off on her own. Now, our shared activity is going for a drive in the car or watching the TV or playing games when my hands do not hurt too much.

Even going for a drive is difficult because we cannot do anything when we get there. Gone are the days of driving to the Peake District or a National Trust property and enjoying a day walking round the home and gardens. At best we now have to take the mobility scooter or Angie has to push me in the wheelchair.

Taking the mobility scooter is great, but it breaks down in to 4 heavy parts and fills the back of the car. Angie then has to put it together while I sit in the car before we can go for a trundle. You are also severely restricted on which surfaces the scooter can actually work on.

I have been told I can get a mobility car but there is at least a 6 month waiting list and I have got to put down a lump sum, which it makes it too expensive to consider. I am in receipt of Personal Independent Payment, but I am having to use that money for the alterations needed to the front door and driveway to allow wheelchair access. The cost of the alterations is £7,500. Thankfully, I have managed to get £1,500 from the MNDA and £1,000 from Adult Social Care in Lincolnshire. This still means I have got to find £5,000.

We have 4 grand-children. I love them to bits, but find it very hard when they want to play and I am unable to take part. Over Christmas we went out a few times but it felt very lonely as they were all running round and I was stuck in the mobility scooter you never walk alongside anybody, you are always slightly behind or in front.

When I finished work, Angie was still working and I used to do the house work and the cooking. All that has finished and now Angie has to do everything. It is so hard watching her do everything and getting tired, when all I can do is sit there.

One of my biggest difficulties is meeting and talking to friends. We tend to make friends based round hobbies and activities. All our friends are outdoor types, some like walking and others like photography... and some like us combine them both.

Whenever we see or speak to them, they naturally tell us about what they have been doing, or are going to be doing. It is so difficult to sit there and smile and say how pleased you are to hear about their activities.

Until this hit me, I would not dream of having the TV on before 6pm and even then only when I was not doing anything else... we did not think about having Prime, Netflix or Disney+, as we would never get the value of them. Now they are my basic staples as the TV can go on at any time of the day.

The hardest thing to contend with though, is 'the wall'. I can be sitting chatting nicely but suddenly I become tired. I have to go to bed. Family members have actually accused me of being miserable and it ruins the day.

There are days when I just do not want to get out of bed.

Going to the toilet in the night or just getting out of bed is a task in itself. We are all used to simply standing up and walking in the full knowledge the body will take us where we need to go..... oh no.. not me.

I have to shift my body so I can drop my legs over the side of the bed without slipping off the bed. I then have to position my stick so I can grab it once I have managed to get upright. I have to position my arms to the side of me so I can support and push myself up using my arms ... I do not have any lift in my left leg and only minimal lift in my right leg.

Until I have managed to stand up, I have no idea whether my legs will support me or my knees will simply give way.

Once standing and holding my stick I can then take my first step and find out whether I can actually travel the 10ft to the toilet.

Taking a shower and getting dressed are just an every day occurrence. Not any more. I am desperate not to become wheelchair bound so I will do everything possible to shower and dress myself ... even if that takes me an hour to achieve and totally washes me out for some time.

I no longer wear clothing with buttons. I have to wear thick long socks because the circulation has gone in my left leg. Getting long socks on can be tricky at any time, but with no control over my left leg/foot and no grip in either hands, it is really hard work.

There are increasingly more days when Angie has to get me dressed and help put my shoes on.

Trying to cut my food is now very difficult. I have no grip in my right hand so holding a knife in my right hand is so awkward. I know I can get a special knife but this is just another example of how my body is shutting down and restricting my ability to look after myself.

I now have to have builders in my house to put in ceiling hoists and convert the front door and drive to accommodate an electric wheelchair.

We had somebody come round with an electric wheelchair so I could test drive it and be fitted for my own chair. Once then man was gone we both sat down and cried.

We have friends who suffer with serious illness and are receiving treatment. They hope their treatment can make them better. When I see or speak with them we exchange our feelings but the one thing I know is that today is the best I am going to be for the rest of my life, for tomorrow I will be that little bit worse, with no hope of a cure.

For the first 12 months, my level of fitness carried me through but now I know I can no longer do the exercises. I feel that if sit quietly then what ever is turning my muscles off does not see any activity and therefore carries on without being alerted to muscle

movement/activity. If I do try and do exercises or try and walk or lift anything, then that seems to send a signal to somewhere and I really notice something happening. With MND you can not build/replace muscle, so every time you feel that burning or feel the pain going through your muscle, you know it is being attacked and you are getting weaker.

The one thing this disease can not do is take away my memories.

I cannot fully express how this disease has and continues to devastate my life. We go for regular coffee mornings at the St Barnabus Hospice, at Novak House in Boston and for those two hour sessions we are taken out of ourselves. The staff there are absolutely tremendous.

I have got to know a number of wonderful people in the healthcare industry, especially the outreach team and Adult Social care.

I cannot speak highly enough of the support given by my MND and Social Care.

Angie and I have become active members of local groups such as the gardening club and the bingo nights at the community centre and we are making lovely friends in the area. We are also members of a games club in Horncastle. As such we are trying to do things which at present I can take part in.

My world is closing in on me and certainly during these cold winter months my view of the outside world will be through the lounge windows.

I can hear the Typhoons going by from RAF Coningsby. I love to see them and enjoyed photographing them and the Lancaster/Spitfire/Hurricane from the Battle of Britain Memorial Flight based at Coningsby.

I have no right to expect to live a full and happy life. I have come to this situation after 62 years of leading a full life. There are millions of people around the world who die at much younger ages than myself and through various ailments and physical disabilities never get to experience the wonderful things I have managed to do.

I wake up frightened and go to bed frightened there are times during the day when my mind is taken off the situation I find myself in. I know my fear is around what is happening to me, but I know it is nothing like the fear Angie has about what our future has for us and how she will cope once I have gone.

I know every spouse or partner losing a loved one causes a massive void, but to watch a loved one disappear in front of your eyes, with no time scale and only the knowledge of what is to come during the time left to them must be the biggest tragedy of them all.

I am caught up in this horrible disease and can do nothing to help myself. I would not mind as much if I had created my own downfall, but to have this hoisted on me seemingly by simple bad luck is very difficult. I know it is too late for me, but can only hope a cure can be found so that others do not have to suffer like this.

The most difficult part to deal with is the knowledge of what is going to happen to me we have all seen celebrities suffering from MND and have watched how their fortunes have changed. I know I am going to be wheelchair bound and incontinent and may even lose my speech. I have already lost my voice.

I have a friend who now has to drink through a straw because she can no longer use her hands. I know of people who have to be fed through a tube as they can no longer eat or swallow. These are all lovely people who until this devastating illness hit them were active members in society and enjoying the fruits of hard work.

We recently lost a lovely man to MND. We have become friends of his widow and daughter and hope they can see their way through the grief of losing a wonderful husband and dad.

I have to watch them in the full knowledge that my wife Angie is going to have to experience the same heartaches but with our nearest family over 140 miles away, Angie will have to deal with all this on her own. I know there will be a lot of support from friends, but they will not be with her when she goes to bed or first thing in the morning.

I know all this is going to happen to me !!!!!