



JOHN'S STORY – Living and Coping with COPD

John Weaving, one of our members, wanted to let others know of his experience with COPD.

“My name is John. I live in Trowbridge and I've been married for 44 years. We have two grown up boys and I will be 65 in July. I worked as a plasterer for 40 odd years, on and off and for a few years in factories. Back last June, my condition got worse and I became quite ill.

While I was still working, I found every day was getting harder and that I found it more difficult to cope each day with the job. I would come home from work and go upstairs for a shower which became a chore as it made me very breathless, especially drying myself. The other thing that became harder was getting dressed – as we all know how bending takes your breath away.

At the end of June, I had an appointment at the Respiratory Clinic for a check-up. When I saw the nurse she asked how I was and I said, apart from feeling puffed out, not too bad. She told me that I didn't look good and checked me over. She wasn't happy with my oxygen level and pulse rate. After putting her stethoscope on the back of my lung she said she wasn't happy with what she was hearing and said she was going to get my doctor to listen. My doctor came in and said he couldn't hear anything but she assured him that it sounded like an organ going off inside me and told him she wasn't happy with my results. She said I was on the borderline and that I should be admitted to the R.U.H.. I told her I wasn't going to any hospital because I would probably be fine in a few days. She said that if I wouldn't go into hospital I had to go home and have complete rest and that I wasn't to do anything at all. In the meantime, my Doctor made me an appointment to see a specialist for x-rays and tests. After spending the best part of a day seeing the specialist, she told me I had to pack up work straight away as it would be too much pressure to carry on.

While I was there, she asked me how I felt about going on the PACE programme, as she felt it would be of great benefit for me. I said I would do anything to improve my health. While I was waiting to hear from PACE, I became very low and was having regular panic attacks. I became very frightened about everything and it got so bad that I had to phone my doctor to tell him how scared I was. He asked me what I was scared of and I told him 'everything' Sitting down, getting up, walking around, going upstairs to the bathroom, etc.. He told me to try and calm down and if I couldn't cope he could give me tablets that would put me on another planet – but to phone him straight away if I still felt the same the next day.

I found it very hard going upstairs – only two or three steps at a time and I had to stop to catch my breath. When I got to the top, I'd stop again to get my breath back ... then there was the coming back down again! I was so exhausted that I would hyperventilate. I sounded like the Titfield Thunderbolt or Thomas the Tank Engine. I even got exhausted eating a meal.

Then there was – going to bed at night (I dreaded it). They were long nights and I couldn't wait for the morning to come around. As soon as I lay in bed, I felt as if I

was going to suffocate. I would get panicky and open the windows and stick my head out just to get fresh air. This would happen all hours of the night. It got so bad that I would struggle to walk to the back room, where my wife was asleep and ask her to come in with me as I was frightened. Just having her in with me made me feel more secure and gradually I would calm down and go off to sleep for a while. This became a regular thing and I would feel bad about disturbing my wife as she needed her sleep.

After a while, I would leave the light on or keep the curtains wide open. I even suggested we both take our mobile phones when we went to bed as it was exhausting for me to go and get my wife. Eventually, I began to listen to my Walkman with the head phones on or play a CD and I found that this would calm me down. Whenever I felt panicky, I would say to myself 'come on, buck yourself up, stupid'. I then rephrased COPD as 'Come On, Panicking's Daft'! I found it hard to cope each day. I went from being a strong and fit person to a weakling; I became drained.

Then, after a few weeks, I received a letter saying that I should go to Trowbridge Hospital to see about the PACE programme and that's where I met Regitse and Lisa. After a while, I received another letter saying they were starting the PACE programme and suggested that I attend the Devizes Community Hospital in a few weeks time. By this time, I was feeling a little bit better in myself and wanted to start doing little things, like attending to my shed in the garden and most of all, go down to my allotment. Well, this seemed to clash with going to PACE and I wanted to go to my allotment rather than go to PACE. I nearly phoned to cancel but anyway, I started going to PACE but had other things on my mind. Not being rude, I didn't really take too much in to begin with because my mind was elsewhere, wanting to be doing other things. Me and a few more there, thought this was a load of rubbish! (Talk about biting the hand that feeds you!) Then we had the exercise and the talks and we all came out with a load of literature which I just put in my folder. I can say now that I didn't look at it.

That's where I met a friend called Kath. We seemed to just click. When we got together we would often comment about what did these people know about how we felt and they were just talking rubbish. Little did we know, at the time, how we were going to benefit from all of this. One day, Val turned up to give us a talk on how ill she had been and how close to death's door she'd been. Yes, Val, I did listen to you and can now say that listening to you gave me a big boost. I thought, how come you've come from being so ill to how you are today? When I first saw you, I thought you were one of the nurses, not one of us. I thought what's she on? – I'll have a pint of that! So, after that I thought, with a lot of hard work and determination, I could be like that too.

About three or four weeks into the programme, I thought 'well, while I'm here, I'd better start doing some exercise and listen a bit more'. I started to knuckle down a bit more and got stuck in to listening and doing more exercises and funnily enough, I began to feel better and stronger in myself. Every time I went back, I would do a bit more and finally I began to feel really better in myself and so did Kath. Anyway, it came to the last week of the programme and Kath and I realised we were stronger in ourselves so we really did take everything back about what we had said about the programme. We were feeling better in ourselves and that it really was making us feel better.

What did it for me: I got fed up with listening to the radio at night and I thought I would look through some of the literature that I'd brought home and there it was, staring me in the face all the time – THE FIVE ASPECTS OF COPD: ENVIRONMENT, THOUGHTS, FEELINGS, PHYSIOLOGY AND BEHAVIOUR. It talked about being POSITIVE and not NEGATIVE. Putting COPD in its place and not letting it control you but vice versa.

I'll never forget the last day when Regitse asked me what I felt about the programme. The only word I could think of was 'Brilliant'. My quality of life had changed so much. After we finished the programme a few of us were asked if we would like to join a Gym. Me and Kath said we would, so Lisa sorted the paper work out and me and Kath joined the Westbury gym where I have been going ever since and have never looked back. Soon enough, I was doubling my exercise programme. Kath gave it a go for a couple of sessions but it got too much for her in the end but she is 81 years young. Getting back to PACE – I can't ever give them enough praise for putting me on the right road and I'm sure that goes for Kath too. So, all I can say is thank you to PACE for what you did for me and all the others. I will never be able to thank you enough. Keep up your good work. I'm sure there are many people out there that can say the same. Thank you very much. I must thank Breathe Easy as well for what they do. I've met so many different people which is a tonic in itself. People with the same illness as me – because together we can improve our quality of life.

I would like to finish by saying, if you knew what Kath's been through – losing her husband two years ago and having two strokes. For someone of 81 years old, going to PACE and the Gym, doing her home exercise and still smiling and most of all keeping positive – I take my hat off to her. Well done Kath.

We can all live with COPD. I know because I haven't let COPD beat me. I'm too positive for that – I'm wearing the trousers now. You can cope with it but I am teaching myself to cope without it. When I was working, I used to say to my mates, "I'm too busy to come to work". Now I say – "I'm too busy to think about COPD". When I first started PACE, I was asked what goals I have in life. One of these is now to help people with the same illness as me because that would be paying back the people that helped me. PACE gave me the choice of what road to take and I did.

The main three things I do are:
Being Positive
Exercising
Mind over Matter.

If I could go back 9 months ago, I would never believe I'd be here today telling you about how I was. It took over so fast; it was as if somebody else had taken over my life.

I OFTEN THINK, WHAT WOULD HAVE HAPPENED IF I NEVER WENT TO PACE. I THINK I KNOW THE ANSWER TO THAT."