

## **Testimony**

**Barbara Kell**

Dear Secretary,

It seems strange to be writing this to you as if you are my friend and potentially hoping for you to give me some help when I really don't feel that this is the case.

I used to have a lovely life, envied by some of my friends. I have a lovely caring husband and two beautiful daughters, my parents are good kind loving people and I had a fantastic social life involving lots of traveling and entertaining. My passion for cooking meant I always had a house full of people to appreciate the time and energy I put into this my favourite hobby.

The change in my lifestyle came quick and drastic. In April 2004 I was going along nicely although a bit less energy than I had previously had, then BANG on the 1st May I suddenly collapsed and could not get myself pulled round. I was diagnosed as having iron deficiency anemia for which I was treated. My iron levels rose to normal but I never got better, in fact I slowly continued to deteriorate. I tried my best to carry on with my life as before but it was becoming increasingly hard to do.

Every time I went out with my family or friends I worried "How am I going to get back to the car"? Until it got to the stage where I could not leave the house. My GP did all the USUAL tests which always came back negative. I could never understand why my GP did not send me for the more unusual tests. I went around in circles like this for three years before finally seeing a consultant who diagnosed me as having ME.

His advice went against all previous advice given which had been to carry on with my life as normal and I would eventually become better. He advised me to pace myself very carefully and prescribed a number of supplements to support my Mitochondria and my heart which had begun troubling me.

The NHS do not like patients with ME/CFS. We are a nuisance, they do not know what to do with us. In fact they are actively advised not to give us any sort of medical treatment or tests which would show biomarkers to validate our illness. For this situation I blame the CDC for trying so desperately to redefine our illness and leave so many of us untreated. I also blame the

psychiatric lobby here in the UK who have wasted all research funding for ME by insisting the illness is in our heads. I blame the NICE guidelines to GPs which manacle the doctors and make them afraid to treat us. Those doctors brave enough to try and help us are immediately jumped upon by The General Medical Council and have restrictions put upon them or their licence to practise taken from them. Leaving us, the patient with nowhere to turn.

The USA and UK governments have I believe colluded to keep the real pandemic nature of this illness out of the media and partaken in moves to make us look like nothing more than hysterical, lazy, depressed people without any motivation and who are attention seekers.

The reverse is in fact the truth. Those of us who are ill are highly motivated and want nothing more than good scientific research and treatments found for us. If it is attention we are seeking we certainly choose the wrong illness. An illness that isolates one from family and friends, that keeps us house or bed bound. An illness that has so much prejudice on it our loved ones often wonder if we are truly ill.

Why didn't we choose MS? A condition with many symptoms the same as ME although in most cases the ME patient is suffering more. If we had gone along to our GP with a diagnosis of MS we would have been sent for all the more unusual tests and offered all sorts of treatments as well as carers to come into our homes to make sure we are well taken care of. None of this happens for the ME patient. We are left to rot, no one cares if we are dehydrated or hungry because we are too weak to care for ourselves. No one cares if we manage to clean ourselves or keep ourselves up to the high standards we once had.

We still have those high standards but lack the energy to help ourselves. My life has changed in so many ways. I now sit at home watching my two beautiful daughters going out together where once it would be the three of us. I see the hurt in their eyes when I have to refuse their offers to take me just 300yards to the beautiful park by our home, or 500 yards to the coast. Every one's life changes with ME. I can no longer be the wife I once was to my loving husband, we cannot go out together and have a social life, we cannot plan anything at all. He feels guilty going out without me so chooses to stay at home too. I am no longer the daughter I was to my elderly parents. At their time of life I feel I should be helping them and doing the things

around the house which they can no longer do, but that is no longer a possibility, so the guilt is mine this time, I can never repay them for all they have done for me and I watch them worry because the only thing they want out of life now is for me to be better. They have lost one child already, how do I tell them that there will never be a cure for me because our governments do not allow the research into finding out the cause and possible treatment for us?

We were given a glimmer of hope in November 2009 when the WPI found a viral link to ME/CFS. But it seems hope was not to be allowed for us. Negative studies were rushed out from all directions, now we have lots of talk of contamination. The WPI are denied funding by the federal government, Dr. Mikovits is denied her papers published. One has to wonder why?

The sick are getting sicker, the illness is spreading, it knows no barriers. Try and imagine one of your family coming down with this monster of an illness. Your Mother, child, grandchild. Think about it because it is almost sure to happen. No one family is going to escape without a patient sometime soon, the disease is growing to quickly.

Try if you can to imagine life without HOPE. I very much doubt it, there will always be a light at the end of your tunnel. That is what we are being handed every day of our miserable lives. NO HOPE

Does it sound like a conspiracy of silence? It certainly dos to me. Will I ever get well enough to have a life again? I very much doubt it. The barriers are well and truly up. Will there be a cure in my children's lifetime? Only if you are willing to do something NOW, TODAY. If you have a family you love and a conscience you will make sure that the WPI and others are funded you will force your friends over the pond to immediately begin scientific research into the illness and you will also force them to give us the respect and any treatments we need. The solution to our health is in your hands. Please use it.

Sincerely,

Barbara Kell