



Jacob's Story – A Clinician's Experience of Being a Patient

My Story ...

My name is Jacob Easaw, and I am a Consultant Cardiologist with special interest in Heart Failure and Advanced Echocardiography.

I am narrating my story so that there will be an increased awareness of this condition called heart failure that can affect anyone, any time and it does not discriminate between age, gender or ethnic background, however much we might assume that we are keeping a very healthy lifestyle. Secondly, for healthcare professionals to understand what it feels like to be a patient and how we approach patients who are suffering with the disease.

My story begins in the autumn of 2018. Having retired and been reemployed in the NHS working part-time I was enjoying my life to the fullest with a very healthy lifestyle, and enjoying my hobbies that I found little time to do when I was full-time employed. My wife and I were planning holidays and we even booked a cruise for the summer of 2019 with friends. However, a few weeks prior to my hospital admission on December 18th 2018, I started to feel progressively tired and fatigued, but put it all down to a recent cataract surgery and the eye drops. I felt I wasn't exercising enough, right up until the evening before my hospital admission. I felt I was in heart failure given that I could see my own raised jugular venous pulsations in the mirror. It struck me, what if I really did have heart failure? However I didn't inform my wife so as not to upset her that night.

Having had a restless night, the next morning at work I immediately told one of my colleagues my symptoms and that I suspected I had heart failure. He immediately did a heart scan confirming an enlarged and very poorly functioning heart with an EF (ejection fraction) of 16-17% (Normal EF between 55-75%). I was immediately admitted into the coronary care unit (CCU) and the news of my admission was gently broken to my wife and my children who were at their respective places.

Immediately, having had the diagnosis confirmed I was upset, and in disbelief that someone like me, knowing about this condition, could actually be suffering from it. I could see myself being connected to monitors, my heart failure nurse giving reassuring messages and my family in CCU with me. It then occurred to me I was actually quite sick, especially when the first dose of intravenous furosemide kicked in and I realised I desperately needed to use a bottle, and understood exactly what my patients have felt over the years. My initial reaction of disbelief and sadness started to worsen as the day went by although I tried to remain calm and composed despite knowing all the facts and stats that I preach day in and day out to my patients. I did feel relaxed whenever a colleague or friends visited me during the day but the nights were the most difficult when everyone had left, I was lying in a CCU bed where I have treated so many patients in my years. I felt it was my turn now to either get



better or maybe it was now my time? I felt emotionally upset, with grief and shock, especially when alone. I hardly slept the whole night with unfamiliar surroundings, bleeping of machines and monitors, nurses coming round the clock to check on me as my monitor leads fell off and there was a flat line with alarms going off and, on another bed, a restless patient extremely agitated, thinking of what all my tests were going to show up and finally would I be going home with a whole bag of drugs or maybe it was too soon to think of that! I could also see my family was putting up with a lot of emotional grief but held a brave front everyday reassuring me that things would get better. In the ensuing days I had a whole lot of tests including an angiogram which I always used to wonder about what would be going through the patient's head when they are told of the risk, albeit small yet still there. Now it was my turn, and despite the fact that it was being done by one of my experienced colleagues all kinds of random thoughts were going through my head. I made sure he gave me the maximum dose of sedation.

As the days went by, I got stronger and I was discharged home on Christmas Eve. For the first time when I walked into my home it was the strangest feeling because normally Christmas is celebrated with family, friends, decorations, presents, etc but this time it was all different. My family and I were together which was an amazing blessing from God but there was an extremely sombre mood, none of the usual stuff. At the Christmas Eve dinner table with my wife and my two children it was not the same. They were also given the news of my serious condition and illness and what outcomes to expect or watch out for. We all had a sense of utter doom and gloom, and hope seemed to fade every time I sighed or coughed. It was great to be back in my own bed but I found it extremely difficult to close my eyes, because of visions that were passing in my head of all the events that had happened in the last few days, and they were incomprehensible. I had a lovely relaxation CD given to me by my heart failure nurse to help with sleep. Although it did help, when overwhelming feelings of a serious illness passes through one's mind nothing really helps apart from calling out loud to God in whom you trust. I pretended that I was sleeping and in fact the first night I felt cold, shivery and trembly and I was sure I had caught an infection. I kept thinking whom shall I call for advice at 2 am on Christmas morning? My mind also told me I was having a panic attack which I have never experienced before. I now realised what the mind can do to a person and how awful it can be for patients when they have them, and then healthcare professionals label them as neurotics. "You really need to get an attack to know what it is like".

The following days passed off uneventfully with encouragement and support from my family, friends, colleagues and my local church. Then there were moments, when I was on my own thinking to myself of everything that had happened in the course of a few weeks, and I started to feel annoyed, and later angry for firstly not suspecting this condition, given that I am meant to be a specialist, and secondly the question "Why me?" I would go through periods of extreme melancholy, tearfulness to extreme anger not really knowing whom to blame. I suppose our natural reaction is for all of us to find comfort in blaming something or someone.



In a short period, I had seen specialists in Papworth, Bristol and St Bart's London. Had more tests and a device implanted.

As with everything in life with time things heal, a pacemaker scar heals, drugs start to work and somehow, I found strength to live a new and transformed life which was my "new normal". I went back to work after three months. My wife and I did the cruise holidays we booked and it's nearly two and a half years since all this happened to me and by God's grace, I continue to live a life to the fullest within my abilities, with daily exercises and doing my hobbies when not restricted by Covid.

Why I am saying all this?

Firstly, we need to understand as healthcare professionals that none of us are immune to any disease and we need to be aware and have things checked out early when we get symptoms, however trivial they may be, rather than assuming we know it all and are infallible.

Secondly, understanding the patient perspective that their symptoms are real to them however trivial or silly they sound to a healthcare professional (HCP). It takes courage, time and honesty for a HCP to explain to patients their disease process, the treatment effects, what to expect and it takes bravery to tell your patients when you don't have an answer for some of the questions that you are asked. The worst is to tell your patient 'Yes' I understand your predicament, because you really don't. It makes the patient feel you are actually ignoring their symptoms without an explanation, or without showing any empathy to their afflictions.

Side-effects of medications are common and many patients find it hard to tolerate them but taking time to explain and making patients understand the benefit of the drugs as opposed to side effects significantly improves compliance. In my current practice when some patients bitterly complain of the side effects of their drugs I confess to them I am on these drugs as well, and experience similar side-effects, but I put up with them due to the evidence of what these drugs can do. In some instances, I even show them my pacemaker scar to convince them I am not only a doctor, but a patient who still sits on their side of the table once in a while. I encourage lifestyle changes with change in diet for weight control, regular physical exercises and encourage them to quit smoking and keep to sensible alcohol intake. Some patients may find it extremely hard to adapt to lifestyle changes but things must be put to them in a sincere and truthful manner, so that they understand they need to keep trying, especially when they give up, and it's important to encourage them never to quit trying. It takes a lot of will power, self-motivation and positive encouragement from HCP. Never write off any patients even if they don't listen to you or take the doctor's orders. Everyone needs a friend and it could be YOU, one day.

