

## Dorothy's story – Living with highly symptomatic AF



My atrial fibrillation story began over seven years ago, but it is really these past two or three years where my life has changed dramatically. From the first episode I have been highly symptomatic and this has intensified massively over the years. My name is Dorothy; I am in my 60s and live in the north of England.

I was diagnosed after my second AF episode in 2009 which put me in A&E and then the cardiac care unit of my local teaching hospital for five days. Here, I underwent a battery of tests, (and also converted naturally to NSR). My BP was found to be high, although no underlying heart issues were found. I was discharged with beta blockers,

blood pressure medication and aspirin to help manage my AF-related stroke risk.

A heart condition! We were shocked; here I was a slim and very fit non smoker who didn't drink, with an excellent diet and a busy professional life dashing about the country. I had excellent health and had hitherto never spent a night in hospital. However I remain convinced that a lifetime of stress and anxiety have been catalysts for the condition as I have really beaten myself up over the years with anxiety (the anxiety of coping, not through giving in to life events). I guess it is a wonder my body has not said 'enough is enough' before. Medics put my condition down to bad luck.

Life got back to normal, I now knew I had this condition, was medicated and probably safer than when I didn't know, so I just got on with it.

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2012 and 2013 brought appalling episodes of AF where I was also diagnosed with atrial flutter and SVT. My episodes (I call them attacks as they are so vicious) put me in hospital for days while I was stabilised, monitored and underwent lots of tests. Until my last huge attack I had converted back to normal rhythm without intervention.

My symptoms are dreadful and intensify with each attack. The chest pain is excruciating, I am given intravenous morphine to ease it. I pass out, the monitors go mad – my BP is crazily high then very low, my heart rate goes over 250. I feel so ill I think I am going to die.

The whole experience is terrifying. For the first time I needed chemical cardioversion with flecainide.

The last attack was so bad that the cardiac registrar sat on my bed holding my hand watching the monitor and telling me when the next huge wave was about to engulf me. He was wonderful and tried to reassure me. Medics thought I had had a heart attack or a pulmonary embolism as I had been on a plane a few hours earlier. Five days later I was discharged and prescribed flecainide to take daily, to add to my beta blockers and NOAC which my cardiologist had prescribed previously. I was referred for an appointment with an Electrophysiologist.

I was so pleased I was on an anticoagulant as my fear of stroke while in such attacks is huge. Interestingly, medics were not sure how to measure my safety as there is no INR check or similar that could be made with a NOAC or there did not appear to be at that time.

Later in 2013 I was having more cardiac tests arranged by the EP when my BP plummeted while on the treadmill and I had chest pains. I was admitted again and spent sixteen days in a cardiology ward to be monitored, stabilised and to undergo a myocardial perfusion test and an angiogram which came back fine.

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I am on an ablation list of which I am told I will need three complex procedures in order to try to get up to 70% relief for up to five years hopefully if they work.

Between some attacks I do not recover well with some very strange symptoms like face numbness, feeling of unreality, feeling I am about to pass out and obviously a fear of going out alone. At one point I was referred by my cardiologist to a neurologist but nothing was found.

My body reacts terribly badly to my AF/atrial flutter/SVT attacks. My whole body goes into chaos and meltdown for weeks and sometimes months afterwards. I can only assume it is because my body is so wracked and overwhelmed at the time. My whole

system, body, brain and emotions are shaken to the core. I am not exaggerating one bit please believe me. I feel as though I have a time bomb strapped to my chest not knowing when it will next implode.

My biggest fear, as every episode gets worse, is what on earth can I expect of the next one and will my body be able to cope.

I no longer work, and fear going out alone in case of an attack. Holidays abroad are no longer feasible. I miss the original bubbly, vibrant me as does my amazing supportive husband.

I live in hope of any medical advancements and dream, quite literally, of a superman/woman EP flying in to rid me of this horror – anyone out there!!

Meanwhile I carry on counting my blessings. I feel the fear, feel dreadful but still do things none the less; I will not be completely browbeaten. I am still me somewhere underneath all this.

**Dorothy, South Yorkshire (2014)**