

## Trevor's story – A husband's perspective



My name is Trevor and I am in my early 50s. My lovely wife Dorothy has had highly symptomatic atrial fibrillation since 2007 and latterly atrial flutter and SVT have been added to the mix. I hope to be able to share with you the trials, tribulations (and fibrillations) of our life since Dorothy's diagnosis.

Compared to the dreadful, deadly diseases many people are sadly afflicted with, we know that AF in itself by comparison, is not up there with the worst. Assuming there is no underlying heart disease and stroke risk it is contained with appropriate medication. (Try telling Dorothy it is not life threatening while in the midst of vicious attacks because it sure feels like it!).

Little did we know when the first episode presented itself in 2007 that the condition would eventually impact so heavily upon us both. An ECG taken after the first episode showed no sign of an issue as by this time normal sinus rhythm had resumed. We put the first episode behind us and continued with our normal life.

2009 saw a much more insidious episode which took Dorothy into our local hospital's cardiac care unit where she was diagnosed with AF. Five days as an inpatient with every test in the book undertaken showed high BP but no further underlying heart concerns. However, a slight increase in troponin levels in the original blood test was noted.

A heart condition, high blood pressure - we were shocked. Here was a woman 8.5 stone, non-smoker, no alcohol, had an excellent diet and exercised regularly with high fitness levels. No familial heart disease of note. We are certain that a lifetime of stress and anxiety and latterly high BP have been the prime catalysts.

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Once over the episode life returned to normal, thinking, ‘well now we know and are safer than before because we have a diagnosis and treatment’ – wrong!

2012 and 2013 brought some huge terrifying attacks which needed hospitalisation from between five and sixteen days at a time for stabilisation, monitoring and a battery of tests, including myoview and angiogram all of which came back fine. Dorothy had a referral to a neurologist to try to isolate some of the weird symptoms accompanying her AF - it came back negative too. Every attack became far worse than the last and it was worrying what on earth would come next.

It was dreadful to see such horrendous symptoms overtake her, to watch the mad activity showing on the monitors, witnessing her passing out. The pain and fear she was going through was heart wrenching. My wife is a strong vibrant woman normally but these attacks floor her – literally.

Seeing a cardiac registrar sit holding Dorothy’s hand watching the monitors, and telling her when the next tsunami was about to hit was dreadful. Intravenous morphine was given for the pain and intravenous flecainide to convert to normal sinus rhythm (NSR). Dorothy normally converts to NSR naturally but not this last time. Flecainide, atenolol and a NOAC have now been prescribed.

Dorothy is now awaiting the first of three complex ablations which we are told *may* give her up to 70% relief after three procedures for up to five years *if successful*.

Our life has changed drastically, the impact huge. Dorothy says it is like walking around with a time bomb strapped to her chest not knowing when it will next explode, living her life on a continuum between fear and terror depending on the symptoms she is

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experiencing at any one time. Dorothy is no longer working, nor does she go out alone. She is generally in a state of anxiety not knowing when it will strike again. Holidays abroad have stopped as have our plans to spend half the year abroad as the risk of having to be hospitalised abroad and with foreign language issues, it is now not a viable option. Our plan had been to take early retirement and travel the world. Dorothy is slow on her medication and often feels in a fog.

For my part, I worry when I leave her while I go to work and am so sad for her. I just want to do whatever I can to make things right for Dorothy and to get her some peace. We live in hope that somewhere, somehow we can get her life back on track and find some relief. I miss my bubbly, enthusiastic best girl!

**Trevor, South Yorkshire (2014)**