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My experience of Constrictive Pericarditis

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Opinion

In April 2010 I noticed that almost overnight I had developed a "beer belly" and as I do not drink much and am normally slim I became concerned. About the same time suddenly I became breathless, easily fatigued and developed swollen ankles caused by fluid retention. I made an appointment to see my GP and was referred to the local hospital for an ultrasound which indicated a swollen spleen and liver.

For about 6 years I had been under annual observation for a blood condition which was originally called Myelodysplasia but which was later described as Chronic Myelomonocytic Leukaemia or CMML. This did not cause me any discomfort and I mention it only because I have been told that it can produce similar symptoms to Constrictive Pericarditis.

Initially I was referred back to the consultant Haematologist who satisfied himself that my condition was unlikely to be blood related and he referred me on to a Cardiologist who sent me for a series of tests and examinations which took place over the succeeding months and which included the extraction of bone marrow, an angiogram, CT and MRI scans, referral to a Tropical Medicine Specialist who in turn arranged for tests to see if I had TB (QuantiFeron Gold and Mantoux) both of which proved to be negative.

The Cardiologist made a diagnosis of Constrictive Pericarditis which was said to be a rare condition that some doctors may not recognise and diagnose; he also stated that there existed little data on this condition and that its cause was known in only 50% of cases and of those known 15% were found to be TB related. Thereafter I was referred to a Respiratory Medicine specialist who stated that I had probably been exposed to TB as a child and that I needed to undergo medication for 6-9 months to prevent the occurrence of this disease as my immune system was compromised; the term chemotherapy was used which caused some concern but this was alleviated by the description anti-TB anti-biotic treatment being applied. When I was a child in the 1940/50s TB was very common.

After the diagnosis of CP I was referred to a thoracic surgeon who told me of the need for an operation to remove part of the pericardium to reduce the constriction on my heart; my heart was not the problem – only the hardening of the pericardium. The surgeon informed me that the operation carried a morbidity risk of between 10-15% and although the choice was left to me I inferred that the message was that it would be seriously debilitating and unwise if I did not have the operation.

Within two weeks I was admitted to an Infirmary and underwent a pericardectomy which was successful. Thereafter I was detained in hospital for a fortnight, lost almost two stones in weight and developed a significant sleeping problem to the point that after discharge I dreaded

going to bed and for many weeks had to sit up in an armchair or in bed with the light on. It took me approximately 4 months and the reluctant use of Zoplicone to overcome the sleep pattern disturbance.

I was informed that the operation had induced arrhythmia and that a cardioversion was necessary to correct this. The consultant surgeon suggested that this should be done within a few days of my operation but I was told that the cardiologist preferred to delay this procedure. I was placed on a Warfarin regime and took other medication including Amiodarone, Bisoprolol, Fuoresimide, Iron capsules and later after the Warfarin was stopped I had to take Isoniazid and Vitamin B6 to prevent the possibility of TB developing. The Isoniazid would have reacted against the Amiodorone and so I had to wait two months after stopping the Warfarin and Amiodorone before commencing the anti TB regime.

My initial appointment for a Cardioversion was cancelled after pre-admission tests showed I was not sufficiently anticoagulated, and it was another 6 weeks before I had a successful procedure which brought my heart rate down from well over 100 to around 50 beats per minute. However, out of what he described as a need for caution and limited data the Cardiologist requested that I remain on Bisoprolol indefinitely and that the dose be raised from 1.25mg to 5mg daily. I prefer not to take medication if possible and was disappointed that I was required to continue with Beta blockers after a successful procedure to restore my heart to sinus rhythm. Occasionally my heart rate drops to as low as 38 and I assume that this is because of the Beta blockers.

I am not medically qualified and have to respect the opinions of Consultants but I remain to be convinced of the need to continue with Beta blockers months after a successful cardioversion and the need to take medication to prevent TB when I have not had the disease and both TB tests and analysis of the part of the pericardium that was removed indicated that the cause of my condition was not TB related. I would not arrogate what has to be a professional medical judgement but I remain puzzled as to how my heart rhythm can be identified as being stabilised in sinus rhythm if I am taking Beta blockers and would prefer to see how the heart progresses without that precautionary medication. Nevertheless I accept medical advice.

After some weeks following the operation I was invited to attend a 10 week Cardiac Rehabilitation Course and recommended to increase my daily exercise. However, I made limited progress because of the Arrhythmia and it was not until a week or so after the cardioversion procedure that I began to feel significant improvement in my physical condition.

Throughout the period mentioned there was frustration, particularly for my wife, as there seemed to be limited explanations for long delays, for example it was 3 months before I had an angiogram, and I failed to grasp fully what the various procedures and tests were intended to achieve.

Despite the apparently low causal association between TB and Constrictive Pericarditis (I have been informed 1 in 10 in the UK) this was accepted as the likely cause of my condition. Regardless of the negative results from the TB tests and the analysis of part of my pericardium the respiratory medicine consultant insisted that there was overwhelming evidence that there was a TB link. When asked what this evidence was he said the fact that I had CP and that during one of my x-rays a calcified spot had been identified on each lung indicating contact with TB. In my opinion that is at best circumstantial evidence but I have to accept what a medical expert says. Perhaps this was an additional precaution because my work had taken me to some global TB hotspots but at the time that was not stated as a reason for the treatment.

From the outset an operation was mentioned as a possibility but it was not until well into the course of the diagnosis that this was confirmed as the best and life enhancing/saving option. Of course the possibility of death was present but was not something that particularly concerned us. More to the point was the fact that our lives were on hold for an indefinite period with no guarantee that I would return to normal fitness and the ability to resume the extensive travelling that was associated with my work and a charity which my wife and I run in Zimbabwe. Of course I understand that there was no way in which the Consultants could have offered any certainty of outcome.

Fourteen months after initial symptoms developed I now feel very well and grateful for the care that I received. I believe that I am as normal as it is possible to be at the age of 71years. As far as I am aware the CMML remains benign and was nothing to do with the CP.

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