

# Experience of atrial fibrillation

Alan Kilshaw's story

I am 67 and first experienced palpitations or fluctuations in my heartbeat over 10 years ago. I thought that it might be of help to members of the AFA if I shared my experiences with you. I suffer from paroxysmal AF.

## VISITING THE DOCTOR or CONSULTANT

I find these visits to be very difficult as I become tongue-tied and often cannot adequately describe symptoms. I am sure that many of us will have come away from a consultation without raising points we wished to make.

Fortunately on some occasions I was fibrillating at the time of the appointment and so that made things much easier.

The following two points may be helpful: -

1. Keep a health diary recording how you feel each day and the effect of drugs you are taking. For example, I could not understand why I often felt as though I was going to pass out and on other occasions it took all my time just to undertake simple every day functions. ECG monitoring revealed that I often experienced a low pulse rate, a condition known as bradycardia. I was in the unusual position of having a very high pulse rate sometimes, and at other times far too low a rate. Beta-blockers were being prescribed to make the pulse rate stable but it was not until a consultant recognised that the dosage prescribed was too high that my life was made a great deal easier.
2. When visiting the surgery/hospital it can be useful to make brief notes of the points you would like to discuss but do not make the list overly long. On one occasion I handed my list over to the doctor.

## ALCOHOL

My experience is that if you have AF do not drink at all. If you have been prescribed warfarin you should only drink very modest amounts anyway.

## PULSE RATE

Make sure you know how to take your pulse and what the correct pulse rate is for you.

## LIFESTYLE

You should consider your health above all other priorities. When I was 60 I was made redundant and I took on a job that was beyond my, then, capabilities. I stayed in this position for two years but then jumped out of the fat into the fire by joining a firm that meant moving house. The stress caused by these decisions made my condition much worse. So, do be careful to take all factors into account and carefully weigh up lifestyle choices.

## HOUSE MOVE

Moving house and into a different NHS area meant I had to start from scratch again with a new doctor and consultant. It took a while to see the new consultant but he was extremely good and decided on a series of tests to thoroughly review my case. I was put back onto warfarin and over a period of a couple of months an echocardiogram, ECG monitoring and a cardiac arrest MIBI/RTF scan were arranged.

## NO MAN'S LAND

I had an ECG monitor fitted for seven days but did not suffer from AF during this period. Subsequently I became quite unwell. I was in a situation where the GP said there was nothing she could do as she had referred me to a consultant. My next appointment with him was in three months time. After several calls to the consultant's secretary she gave me a cancelled appointment in about a month's time.

While I had been told that my condition was not considered life threatening I find the situation when I'm experiencing palpitations quite difficult but do not wish to just "turn up" at A & E or call an ambulance. It would be helpful to be able to call someone in these situations with specialised experience just for reassurance. The AFA are very helpful as discussed later.

## ABLATION

I have had two procedures. One was to correct "flutter"; the other was a pulmonary vein ablation (PVA) to correct fibrillation.

The operations are complex from the surgical viewpoint and can, I understand, last from 2 to 6 hours.

The most important things to remember are: -

- > You are given sedation drugs. You could be asleep for most of the operation
- > There is a short period of some pain. This does not last
- > The consultant likes you to keep still
- > You will almost certainly be discharged from hospital the following day

I believe there is usually a waiting period of between two to four months for the procedure. There are not many hospitals with the necessary equipment.

## POST-OP

There can be after effects particularly with the PVA procedure, for example:

- > Arrhythmia can recur in the first two to four weeks after the ablation

- > It can take 1-3 months for the ablation scars around the pulmonary veins to totally heal
- > If AF recurs, you are advised not to be alarmed; it is part of the evolving healing process after the ablation
- > If it is persistent, you should visit your GP
- > It is not uncommon to experience extra heartbeats on and off for a few weeks after the procedure, until the small scars created in the heart heal

I experienced the above and also a vibration or a quiver like effect. I was convinced that AF had returned but importantly my pulse rate was steady. This was borne out by ECGs and holter monitors taken at intervals over the nine months following the operation.

However, I am still experiencing these symptoms from time to time. My next visit to the consultant is scheduled for August 2013.

## **ASSISTANCE**

I became aware of the AFA rather late, about eight years after the original diagnosis. I found their brochures to be well written and very informative. I have also used the 24 hours help line and this has been excellent. Sometimes you need to talk to someone. (I live on my own)

The web is useful as well but be wary how you use and interpret information.

I found the NHS professionals from the practice nurse to the specialist consultants to be excellent and extremely helpful.

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