

My Amazing Maze

By Kerry Acker

I was diagnosed with afib in early January of 2003. A full battery of medical tests showed no heart disease, a normal sized left atrium and no other medical conditions that would cause my afib. It took me six months of consultations, research and trial and error to determine the most effective medical and lifestyle regimen. With the help of this board, I learned that I was a lone vagal persistent afibber and settled upon the following regimen:

- 1. Cardizem, which kept my heart at a safe and relatively comfortable rate during my episodes, which usually lasted 15-20 hours. Although my rate was comfortably low, the arrhythmia was usually very uncomfortable and resulted in considerable anxiety, discomfort and feelings of dread.
- 2. Flecainide, taken <u>only</u> at the onset of an episode and then twelve hours later. I usually converted within a few hours of my second dose. (Thanks to Hans for informing me about this option.) My EP did not believe this occasional use of flec would be effective, although she did not otherwise object to my plan to use it in this manner. She was wrong and a year or so later, the "pill in the pocket" became an accepted medical practice.
- 3. High doses of fish oil, together with a good multivitamin.
- 4. One full aspirin (325mg) per day.

In addition to the above, I found that the use of benzodiazepines on an intermittent basis helped to control my episodes. After I read a note in Hans' book, I tried using Ativan immediately upon inception of PACs, and found that it would terminate the PACs, and would thereby prevent the onset of an episode. I later switched to Valium, a longer acting benzo, which had the same effect. While I could not prevent all episodes, since many of my episodes were not preceded by PACs, I did obtain some measure of relief with this use of benzos. However, once an afib episode had started, I found that the Valium did not help in converting me to NSR, although in some cases it made me more comfortable. In any event, I recognized that long-term use of benzodiazepines was not a result I wanted or that would be medically desirable.

During 2003, my episodes occurred about once every two weeks. Then, miraculously, without any changes in my meds or lifestyle, I had two years of relative calm. I experienced about nine episodes each year in 2004 and 2005, a major improvement over 2003. Then, literally on the first day of January 2006, my episodes returned with abandon, and I suffered more afib in the first three months of that year than I did in all of 2004 and 2005 combined. I decided that it was time to do heavy research into all available interventional options.

Over the next six months, I met with the EP group at the University of Pennsylvania, a top tier catheter ablation center. I also had a consultation with the Wolf group in Cincinnati about their "mini-maze"

procedure. Finally, I met with a surgeon who performs the full Maze procedure. In between these visits around the country, I did daily reading and research into the available procedures, and I read posts from others who had had them done, queried doctors (and their assistants) through online websites, etc.

Even though I am a relatively young (50) lone afibber, I eventually decided not to undergo a catheter ablation or the less comprehensive "mini-maze". Rather I opted for a full Maze. Even though both of the former procedures are less invasive than the full Maze, I decided, based on the extensive research I had done and discussions I had had, that a comparison of the risk factors and success rates for all three procedures, led to the inescapable conclusion that a full Maze was my best option.

I concluded that both the catheter ablation and the full Maze presented specific and sometimes different risk factors, but in the case of a healthy, fifty year old lone afibber the relative overall risks were not necessarily greater with the Maze. According to my surgeon, the risks of stroke, bleeding or infection are no higher for the full Maze procedure than for an ablation or mini-maze, and some of the other risks of an ablation –esophageal perforation, pulmonary vein stenosis and extensive radiation exposure -- are non-existent in the full Maze procedure.

I was further influenced by the length of time that the Maze procedure has been around. It was developed in 1987 and twenty years of research and practice has resulted in a uniform set of lesions used by all of the top tier Maze surgeons, with the major difference in technique being the energy source used to create the lesions.

I was struck by the fact that while the procedures performed at the top ablation centers have a number of similarities, there are substantial differences in the nature of the ablation procedure, depending on who is performing it. This made me uncomfortable, because it seemed clear that there was not yet uniformity among the EPs as to the best way of doing the procedure. I concluded that more time was needed for the best protocols to be established and adopted by most top EPs, and frankly, I did not want to be one of the case studies that helped them to develop that protocol. (With respect to the modified, or "mini" Maze procedures, although they hold great promise, I believe they are too new to consider right now and, in any event, the success rates are even lower or at best the same as catheter ablations.)

Moreover, I was not particularly impressed with the overall success rate of first catheter ablations (around 70%), with a slightly higher success rate for touch-ups after a first one. On the other hand, when I first met in March of 2006 with the surgeon who later did my Maze, he stated that he personally had had an overall 90% success rate, defined as afib- free, without meds, for at least one year following the surgery. Although he did not have formal data, he expressed the opinion that my age, health and nature of my afib would probably give me an even greater likelihood of success. While this seemed to be an extraordinarily high success rate, I felt confident that he had given me honest statistics after I queried him at length and followed up with my own research. Since my worst nightmare would be to have a procedure done (whether ablation or surgery) and then find that I still had afib, the success rate was a key factor for me.

After careful consideration, I concluded that the full Maze offered me the most time- tested procedure along with the best overall chance of success with a relatively low risk profile.

I chose one of the best Maze surgeons in the world, Dr. Niv Ad who had trained with the founder of the original Maze, Dr. James Cox. Dr. Ad (pronounced "Ahd") has performed more than 500 full Cryosurgical Maze procedures to date. Approximately 200 of those have been performed with his surgical team at Inova Fairfax Hospital in Falls Church, Virginia. Contrary to popular belief, the procedure does not have to be performed using a sternal incision and is far less complex than the original "cut and sew" procedure since the scalpel has been replaced by traditional energy sources, i.e., cryoenergy and bi-polar radiofrequency. Ultrasound and microwave energy are also used. Dr. Ad uses only cryoenergy as he feels it is the safest technology in which transmurality of the lesions can be seen and verified.

Initially I assumed that I would have the minimally invasive Maze procedure, as I had been told by Dr. Ad that I was an ideal candidate for it (no underlying health or cardiac issues, optimal weight, etc.) However,

in my initial visit with him, we had an extensive discussion about the pros and cons of doing the Maze using the minimally invasive incision versus a median sternotomy. During that discussion, Dr. Ad told me that a major advantage of a sternal incision is that the time on heart-lung bypass is far less than with the minimally invasive procedure. In addition, he acknowledged the common sense conclusion that the surgeon would have better visualization of the heart with a sternal incision. Finally, he also advised that the sternal incision is generally less painful during recovery than the incision used in the minimally invasive procedure (which is very similar to the one used in the Wolf procedure). However, he also assured me that the full Maze can be performed safely and effectively using the minimally invasive right side incision. Over the next few months, as my afib continued to plague me and I did more research and reading, I started to seriously consider the median sternotomy. When I scheduled my procedure with Dr. Ad, it was with the assumption that I would be having the minimally invasive procedure done, but he let me know that I could change my mind right up until the moment before I went to the OR. Finally, the day before the surgery. I made up my mind that I would opt for the median sternotomy, because I liked the idea that the surgeon would have better visualization, and I particularly was more comfortable with the idea of significantly less time on bypass. When I saw Dr. Ad on the morning of surgery, I told him that I wanted a median sternotomy, and therefore the procedure went ahead in that manner. However, I stress that this was a personal decision, and that the procedure, in all likelihood, would have been just as effective had I elected to have the right side incision instead.

The actual surgery takes about an hour, and I was hospitalized for about four days. I had a few minor, expected and totally controllable complications of the surgery which were dealt with while I was still in the hospital. Because I had traveled from out of town to see Dr. Ad in Virginia, I remained in the area for about a week after I was discharged, just in case of any complications.

Post-operatively, I was fortunate to have the luxury of taking plenty of time to limit my activities, primarily due to the sternal incision. I was restricted from lifting more than 5 pounds, and many other normal daily activities (such as driving, or even sitting in the front seat of a car) had to be put on hold for about 6-8 weeks, although I could have returned to work in two. (With the lesser invasive incision, full activities can be resumed much more quickly.) I experienced some discomfort in the area of my incision for a few weeks, but it was controllable with medications, and, as indicated above, the pain with a minimally invasive incision is often worse because of the cutting of certain nerves. The only pain I experienced was when I coughed or laughed but this went away in about two weeks.

I recently marked the six-month anniversary of my surgery, and I have been afib-free since day one. Up to 50% of patients experience some post-op afib for up to three months after surgery. This is expected and if the procedure has been successful, the afib generally disappears after about three months. I was very fortunate to be free from afib immediately after the surgery, as well as from PACs and other uncomfortable symptoms that had previously been associated with my afib.

Other than fatigue and weakness for about four weeks after the surgery, the recovery has gone very well and I now feel back to normal. I have resumed my cardiovascular and weight training and I am no longer concerned about eating or drinking anything that might trigger an episode.

One of the other advantages of the Maze surgery is the ability of the surgeon to deal with potential causes of afib if discovered during the procedure. In my case, Dr. Ad tested my Ligament of Marshall and, not surprisingly, got a very strong vagal response. This small ligament is vestigial so snipping it does not affect heart function but eliminates any possible role that it may have in atrial fibrillation. However, deactivation of the Ligament of Marshall can cause a temporary increase in resting heart rate, which I did experience. That has slowly subsided and will probably improve over the next few months, although the current rate is perfectly acceptable and given the vagal nature of my afib, may even be preferable.

The final step in the procedure is closure of the left atrial appendage, which is known to be a primary source of clotting, and hence stroke. Many surgeons opt to remove it entirely, but because there may be some hormonal functions performed by this appendage, Dr. Ad chooses instead to oversew it. I am well aware of the studies showing that lone afibbers are not at any greater risk of stroke than the general

population. Nevertheless, if my afib does ever return, I will sleep just a little better at night knowing that a primary source of clotting has been shut down.

I have no doubt that I made an unusual decision to opt for a full Maze, in that most relatively young lone afibbers would probably go for an ablation before considering surgery. However, given the relative risks, options, and likelihood of success, I certainly would encourage any chronic afibber who is considering some form of interventional therapy to at least consider and research the full Maze.

Only a handful of surgeons in this country qualify as top-notch Maze surgeons, and they are primarily located in major metropolitan areas. However, most of these surgeons do not have the extended waiting time that is the usual for top ablation EPs. Shorter waiting time might also be a factor for those whose afib may have taken a sudden turn for the worse and might be looking at a year-long waiting list, with the possibility of a second procedure, in the case of an ablation.

I lived with afib for several years, some worse than others. In the end, I could no longer tolerate the uncertainty and discomfort of this condition as I entered my sixth decade of life. Some of the people closest to me could not understand how I would elect to have what they thought of as "open heart surgery," when my afib was only intermittent, and probably not life-threatening. However, I was always aware that another episode was just around the corner, and even when it wasn't, I always felt that it was. I found myself restricting enjoyable activities, modifying my diet in ways that were not acceptable to me (and often didn't make any difference anyway), and in general, I always felt as though my afib was controlling me, instead of the other way around. Once I met a surgeon whom I felt completely comfortable with and confident in, who was willing to answer my many questions, I felt that a full Maze was the way to go. I went into the procedure knowing that I was taking a risk – a low, but not insignificant one– which I had weighed against the toll that afib was taking on my life. I went ahead, and today, six months later, I am glad I did. It was well worth it.

The AFIB Report is published 10 times a year by Hans R. Larsen MSc ChE 1320 Point Street, Victoria, BC, Canada V8S 1A5 Phone: (250) 384-2524 E-mail: editor@afibbers.org URL: http://www.afibbers.org ISSN 1203-1933.....Copyright © 2001-2010 by Hans R. Larsen

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