



A Letter to Fellow AFIB Patients

Hi, my name is Ross! I'm physically active, exercise regularly, and love to skydive. However, this has not always been the case. A few years ago, my lifestyle was significantly compromised for an extended period of time when I developed an irregular heart beat diagnosed as atrial fibrillation (AFIB). As I progressed through the stages of this disease (paroxysmal, persistent, and finally long-term persistent AFIB), I twisted myself in knots trying to identify and limit potential triggers but my efforts were futile and symptoms prevailed.

We each have a story that brought us to this junction in life. I know what AFIB patients are feeling and I'd like to share what I did to get that energetic lifestyle back. My electrophysiologist presented me with three options: (1) do nothing, (2) get on a drug treatment plan, or (3) undergo a catheter ablation procedure. I wasn't going to do nothing so I reluctantly started the regiment of blood thinners and heart rate and rhythm drugs. Being on medications felt like being on life support so I didn't stop there.

I'm pretty sure AFIB patients and their families would agree; in addition to the physical stress, the disease and medications also generate significant psychological and emotional stress. Determined to change the course of my life, I attended local AFIB seminars, conducted research, and found a website called StopAfib.org. This website was founded by Mellanie True Hills and offers a lot of really great information. The website gave me hope - a life raft at a time in my life when I was floundering in what felt like a dark and ferocious storm. Thank you Mellanie; for all your hard work building awareness and advocacy for patients.

Another wonderful effort Mellanie leads is an annual Get in Rhythm-Stay in Rhythm conference in Dallas, Texas. I eagerly signed up for the event, attended, and learned a lot, to include a fourth option - surgical ablation. An innovator in the AFIB treatment field, Dr Randall K. Wolf, presented his procedure called the Wolf mini-maze. I watched his presentation and met him afterwards to discuss my situation. He listened, was engaging, patient, courteous, and very knowledgeable. The procedure he described sounded logical, comprehensive, and addressed my concerns and major components of this condition in a single operation.

I eventually underwent the mini-maze procedure performed by Dr Wolf, have been AFIB-free ever since, and I'm no longer taking AFIB medications. Post-op, I can also attest to Dr Wolf's outstanding cardiothoracic surgical skills. No surgery is a walk in the park but he and his team made this procedure as comfortable and safe as possible. My heart has now been in normal sinus rhythm for several years. Thank you, Dr. Wolf, for literally getting my life back on track. While Dr Wolf's mini-maze procedure worked for me, I recognize it may not be appropriate for some. Every patient is unique and each is experiencing a different stage of the disease. My advice; talk to Dr Wolf and see if you're a candidate. I find him to be very approachable, respectful, honest, and willing to share his expertise.

I'm often asked how I decided which AFIB treatment option fit me. Like many others, I was overwhelmed with all the information and eventually consolidated my notes into a decision matrix of pros and cons for each option available to me at the time. I've attached a copy of that matrix in case other patients would like to create a similar format based on options and information they've learned. In summary, be proactive, do your homework, consult with doctors and family, collaborate with other AFIB patients, list pros and cons, decide on an action plan, and then execute your plan! Ultimately, this strategy led me out of my storm.

"Act now, Life is short, Time is luck "

ROSS'S PERSONAL AFIB TREATMENT DECISION MATRIX

OPTION 1 DO NOTHING	
PROS	CONS
No medications No surgical risk Ongoing research may discover new treatments	Without treatment, 1 in 3 people living with AFIB will have a stroke in their lifetime AFIB progression (paroxysmal to persistent) at 1 yr 10%-20%, after 12 yrs 50%-77% Persistent AFIB leads to substrate modification, thickening, stiffening, scarring walls Heart muscle remodeling eventually makes AFIB more difficult to treat Declining left ventricular ejection fraction rate (30% in my case) Events cause light-headedness, fatigue, shortness of breath, confusion Unable to maintain aggressive physical conditioning for healthy lifestyle Increase potential for future dementia, fibrosis, oxidation, shortened lifespan May eventually lead to heart failure, need for pacemaker, or heart transplant Over time; physical, psychological, emotional stress greatly diminish quality of life
OPTION 2 CARIOVERSION/MEDICATIONS	
PROS	CONS
No surgical risk Cardioversion (chem/electrical) may restore NSR for some (NSR = Normal Sinus Rhythm) Anticoagulant helps reduce stroke risk by ~60% Meds slow HR, lower blood pressure, increase blood flow May slow progression of AFIB-related heart damage	Cardioversion (chemical or electrical) often needed to restore NSR Cardioversion success rate often not long-lasting (<1 yr ~50-90%, >1 yrs ~50%) Without rhythm/rate control, heart damage listed under option 1 continues Meds manage symptoms, do not block source of chaotic electrical impulses Antiarrhythmic/anticoagulant medication out of pocket drug costs Requires strict medication regimen, typically loses effectiveness over time Potential negative interactions with other medications (now or future) Drugs (i.e. amiodarone, digoxin) can cause organ damage (liver, thyroid, lung, eyes) Side effects: low blood pressure, light sensitivity, confusion, impaired reactions Suppressed HR/BP causes fatigue, tiredness, restricts physical conditioning Capillaries weaken with age, increases future risk of anticoagulant-related bleeding Future surgeries require anticoagulant pause, increasing chance for clots/stroke Anticoagulant restricts hazardous occupations and extreme sports participation AFIB psychological/emotional stress most likely still a factor Medications equaled life support to me
OPTION 3 PVI CATHETER ABLATION	
PROS	CONS
If successful, NSR stops further AFIB-related heart damage <u>Success Rates:</u> <u>Single Procedure</u> <u>Multiple Procedures</u> Optimal candidate: 60-80% 70-90% Moderate candidate: 45-65% 55-75% Poor candidate: 35-50% 45-60% Significantly reduces AFIB psychological/emotional stress May be able to stop antiarrhythmic drugs Tackle AFIB now; reduce future compounding health issues associated with multiple age-related illnesses ----- LAA may later be ablated to stop related impulse source Some medical ctrs offer separate mechanical LAA occlusion or ligation procedure to reduce chance of clots and stroke If PVI ablation operation later followed by LAA occlusion or ligation operation, may be able to stop anticoagulant drug	Varied success rates dependent on medical ctr/doctor/case volume/experience A lot of patients attending AFIB Conf because one or more catheter ablations failed Electrophysiologists don't have direct view of beating heart while ablating Reports of weak transmural lesions, burn/freeze injury to major nerves/esophagus Radiation exposure if center uses fluoroscopy X-ray machine to view catheters Ablation instruments/devices create "spot weld" pattern which can leave gaps Burn/freeze patterns often require repeat touchup ablations to close gaps Multiple dotted catheter burn spots (around PV) scars more heart tissue than straight lesion created using mini-maze radio frequency (RF) ablation clamp Procedure includes punching hole through heart's septum from right to left atrium Catheter ablation operation still has small complication/infection/morbidity risks PV isolation alone does not eliminate LAA possible source of electrical impulses Remain on anticoagulants due to LAA potential for blood clots/stroke Implanted LAA mechanical occlusion device may leak/LAA impulse source remains Requires <u>two</u> separate operations if able to later add LAA occlusion or ligation
OPTION 4 SURGICAL ABLATION (WOLF MINI-MAZE)	
PROS	CONS
If successful, NSR stops further AFIB-related heart damage Dr Wolf availability/experience (17+ years, over 2000 cases) <u>Wolf success rate:</u> paroxysmal (92%), persistent (85%), long-standing persistent (75%) <u>One</u> operation (PVI+LAA ligation), no fluoroscopy (radiation) Precise transmural lesions using bipolar RF ablation clamp Micro video camera used for direct view of heart ablations Ganglia Plexi stimulated/tested/ablated as appropriate LAA excision removes potential AFIB impulse/clot source Very likely able to stop anticoagulant/antiarrhythmic drugs Studies indicate LAA removal reduces systolic/diastolic BPs Ends AFIB psychological/emotional stress Able to return to active lifestyle and extreme sports Tackle AFIB now; reduce future compounding health issues associated with multiple age-related illnesses	Pre-operation anxiety Time, costs, logistical arrangements associated with travel to Texas for procedure Minimally-invasive ablation operation still has small complication/morbidity risks Typical surgery post-op discomfort/minor scaring