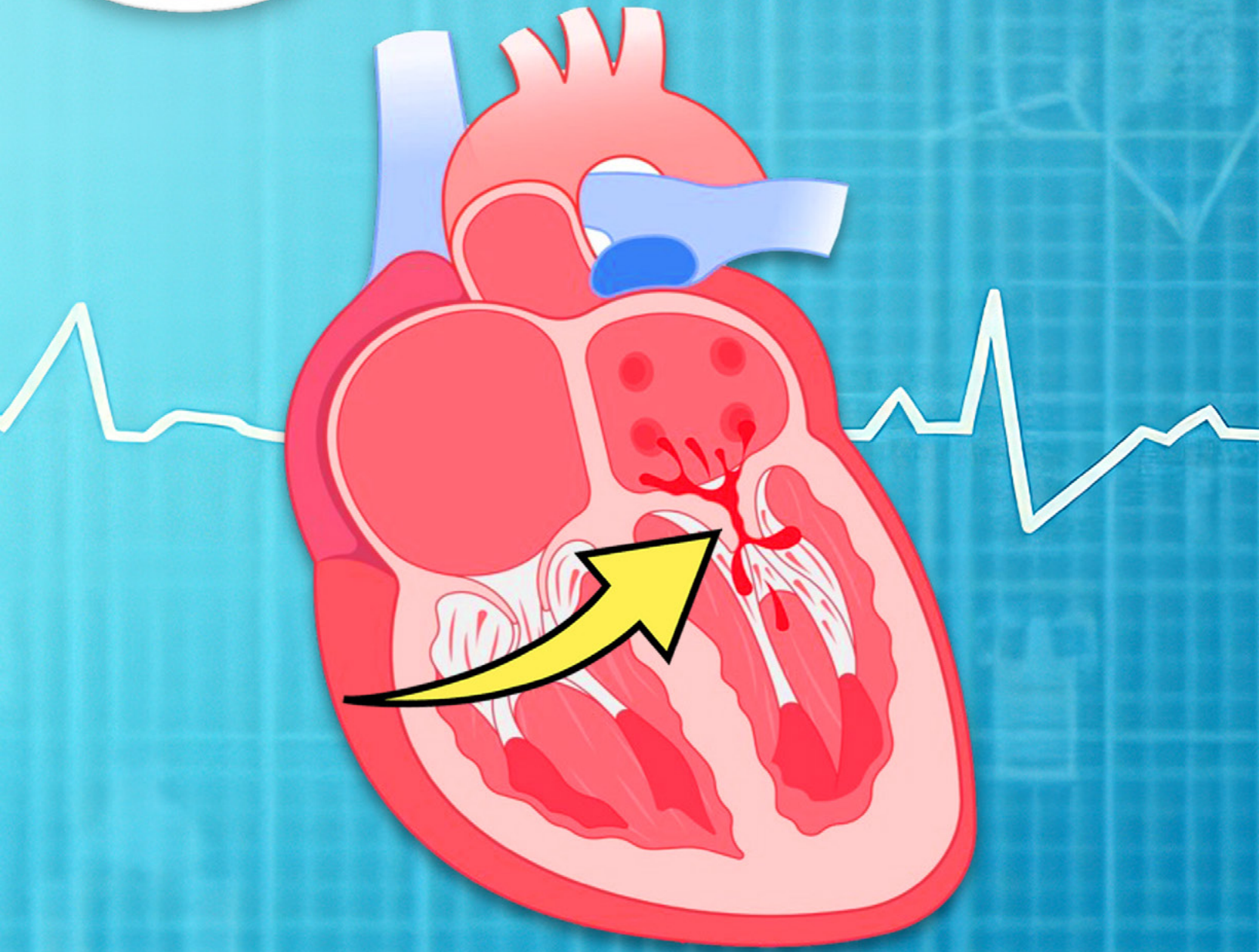
HeartValveSurgery.com

6 EXPERT TIPS FOR HEART VALVE PATIENTS



Northwestern Medicine

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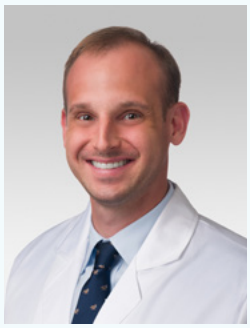

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Please note: A complimentary video playback of this eBook is now available on YouTube at this link.

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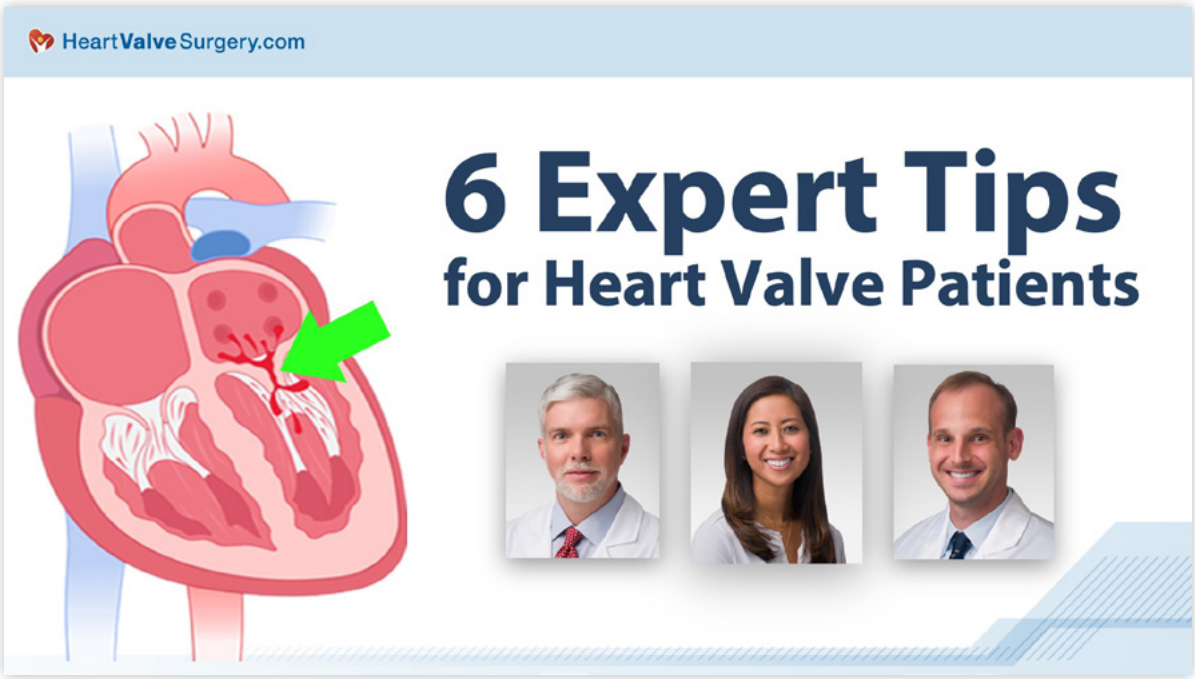


Adam Pick: Hi, everybody, my name is Adam Pick. I'd like to welcome you to the webinar titled, "6 Expert Tips for Heart Valve Patients". If I have yet to meet you, I'm the patient who started HeartValveSurgery.com nearly 20 years ago in 2006. The mission of our website is really simple. We want to educate and empower patients just like you. This webinar, which has had over 950 registrations from patients in countries all over the world, was designed to support that mission. Throughout the webinar, you're going to be in what's known as "listen only" mode, but I would encourage you to submit your questions in the control panel that's on your screen.

Let's look at the agenda for today. I'm going to introduce our featured speakers, we're going to talk about "Valve Disease Day", we're going to reveal six expert tips, we're then going to dive into a Q&A session, and at the end of the webinar, I'm going to ask you to complete a very quick five-question survey. When it comes to the featured speakers today, I am humbled and I'm honored that they are taking time away from their very busy practice at Northwestern Medicine. Who are they?

We have with us Dr. Doug Johnston, who's the Chief of Cardiac Surgery at Northwestern. Dr. Johnston, thanks for being with us today.

Dr. Johnston: It's great to be here, Adam.

Adam Pick: We've got Dr. Melissa Medina, who's a cardiac surgeon and assistant professor of cardiac surgery at Northwestern Medicine. Dr. Medina, thanks for being here.

Dr. Medina: Thanks for having us.

Adam Pick: All the way from Alaska, we have Dr. Kevin Hodges, who's joining us on his vacation. He is a minimally-invasive specialist with a super subspecialty in robotic mitral valve repair. Dr. Hodges, thanks for being here.

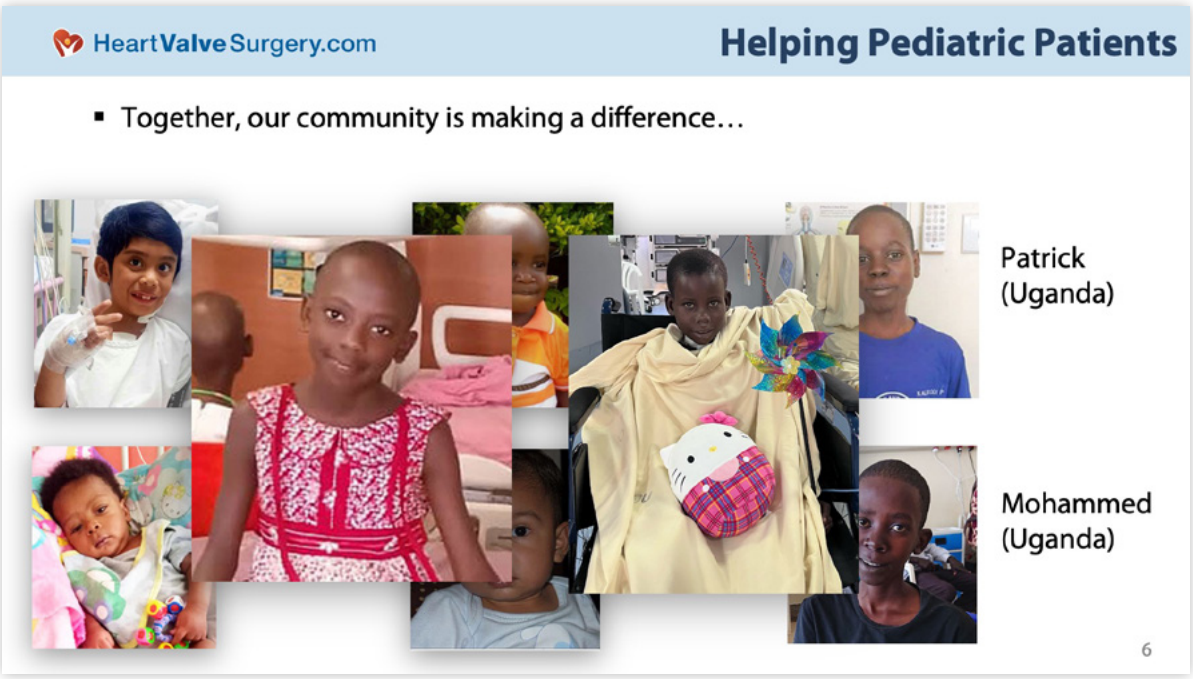
Dr. Hodges: Thanks, wouldn't miss it.

Northwestern Medicine Patient Success Stories

Adam Pick: I could go on-and-on about the achievements and accolades of these three physicians. They have performed collectively, not 50, not 100, not 1,000, but several thousand heart valve procedures. Instead of going into all the research that they've done, all the clinical work that they've done, what I'm going to do, given the agenda, is simply show you this. These are the pictures of the smiling faces from patients at HeartValveSurgery.com who have gone to Northwestern Medicine and had some extraordinary outcomes. Whether it's David or Jesse or Paul or Michelle or Alan or Lawrence, it is wonderful to have Dr. Johnston, Dr. Medina, and Dr. Hodges on the line.

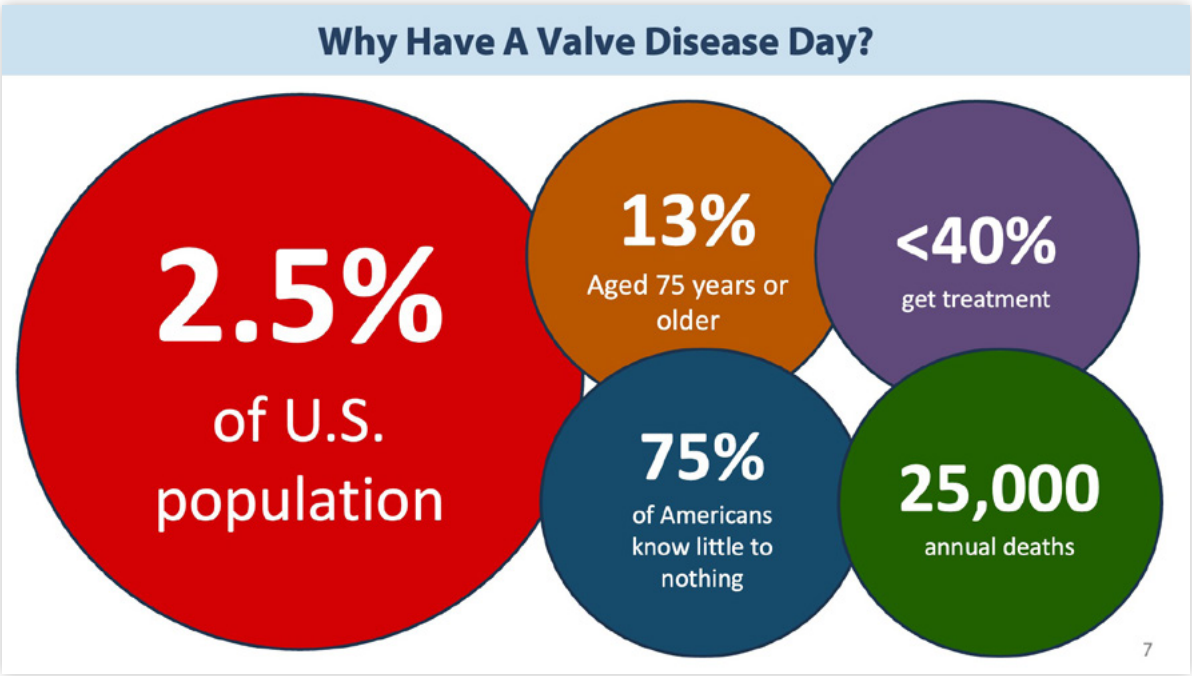
I also want to congratulate Northwestern Medicine on the 20th anniversary of the Bluhm Cardiovascular Institute, which happened last week. I was very lucky to be invited to attend their celebration of this incredible accomplishment. It really is a testament to what happens when good people come together who want to do good things.

HeartValveSurgery.com Community Giving Back



Adam Pick: I'd also suggest to you that's what's happening here at HeartValveSurgery.com. As many of you know, one of my passions is helping children in third world countries get cardiac surgery treatment. To date, we've helped the six children that you see in front of you here in the Philippines and El Salvador and Uganda, and just recently we helped Nsmire in Uganda and Daphine. Daphine just had a mitral valve repair. In the spirit of today, we are a community coming together to learn more about our health and learn more about our heart valve care.

National Heart Valve Disease Awareness Day



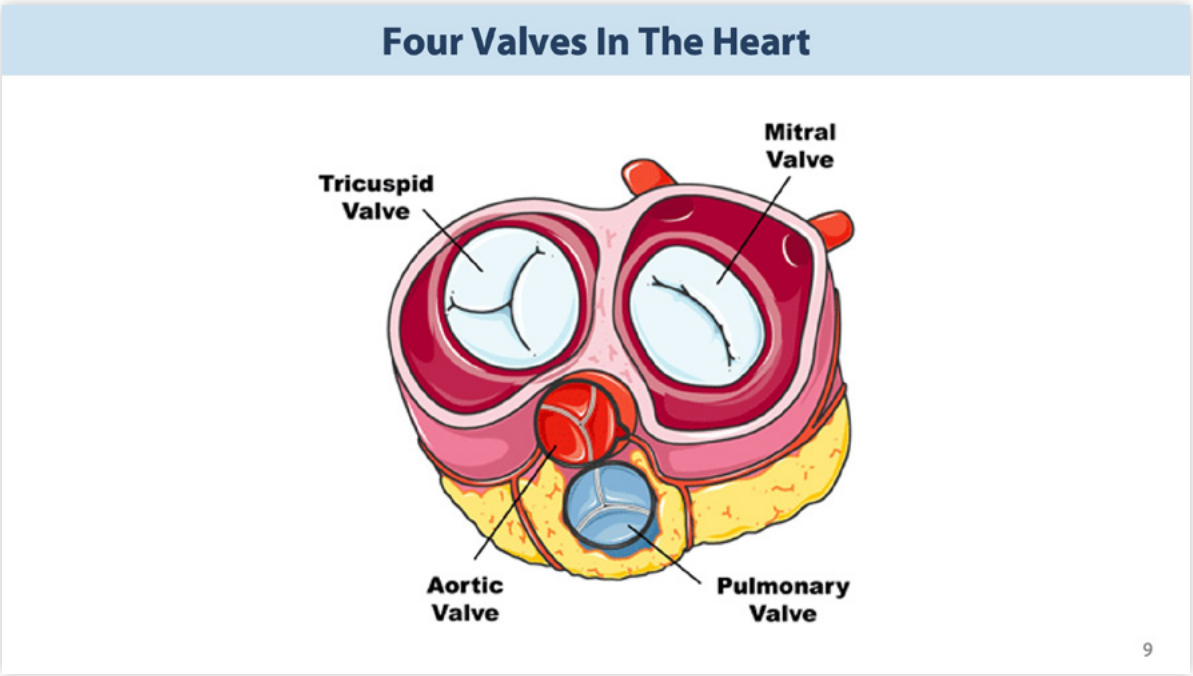
Adam Pick: Let's talk about this thing called Valve Disease Day. What is it? Let's start with the facts. The facts are about 2.5% of the population have some form of heart valve disease. It might be trace, might be mild, might be moderate, might be severe, but it's a good amount of people in the United States. Because the disease is degenerative, you'll notice that as you get older, more people have it. About 13% of people over the age of 75 have some form of valve disease.

This is where Valve Disease Day comes in. 75% of Americans know little to nothing about valve disease. It's a very unknown disease, and it's very insidious because it can be asymptomatic. What makes this even worse is the fact that less than 40% of people with the disease get treatment.

Sadly, when you look at the data, about 25,000 people die annually because of a valvular defect. This is why we're here today. It's to raise awareness to this disease.

How are we doing this? Back in 2017, we started Heart Valve Disease Awareness Day, and it's a group. It's not just our community. It's a group of many other folks who are doing this. It's over a hundred organizations that have come together. It's recognized by the US Department of Health and Human Services. To date, I'm very proud to say that we've generated over 1 billion impressions that reached 166 million people, help them learn about what valve disease is and what valve disease isn't.

Heart Valve Anatomy

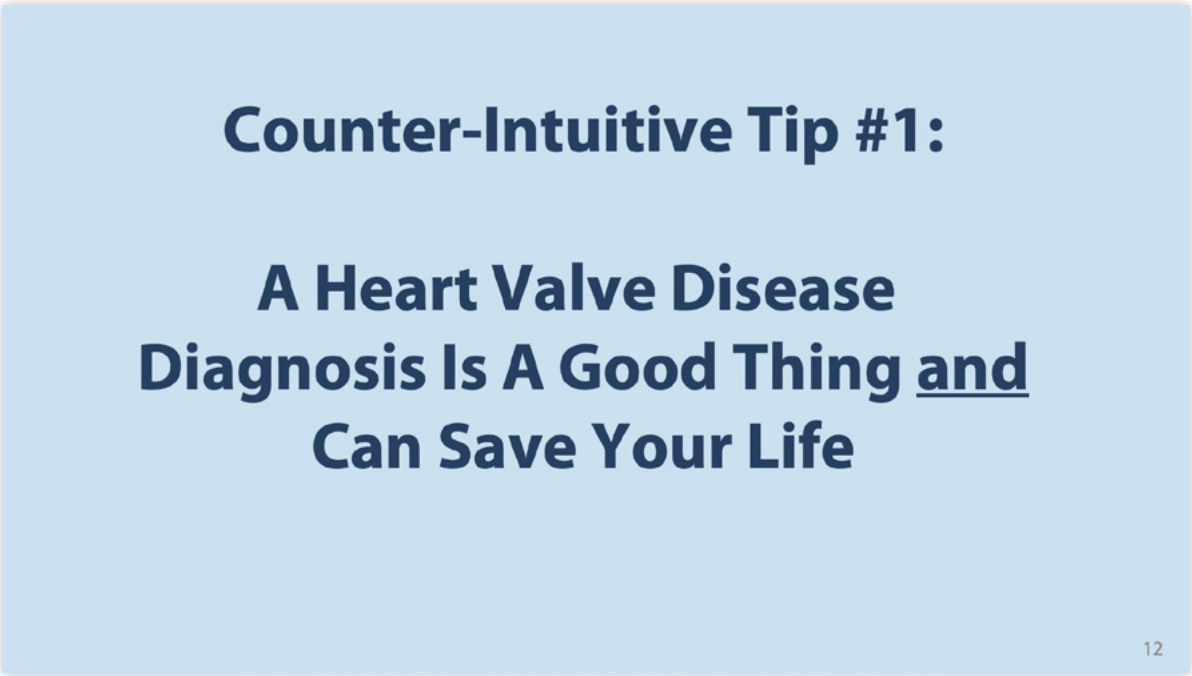


Adam Pick: There are some people on this line who may have been diagnosed today, and so to level-set for them, I just want to ensure that you have four valves in your heart. There's the aortic valve and the mitral valve, which are most commonly valves that are treated, tricuspid valve, which is often referred to as the "forgotten valve", but is coming online very quickly with a lot of new technologies to treat that, and then there's the pulmonary valve.

Heart Teams Ready to Help You

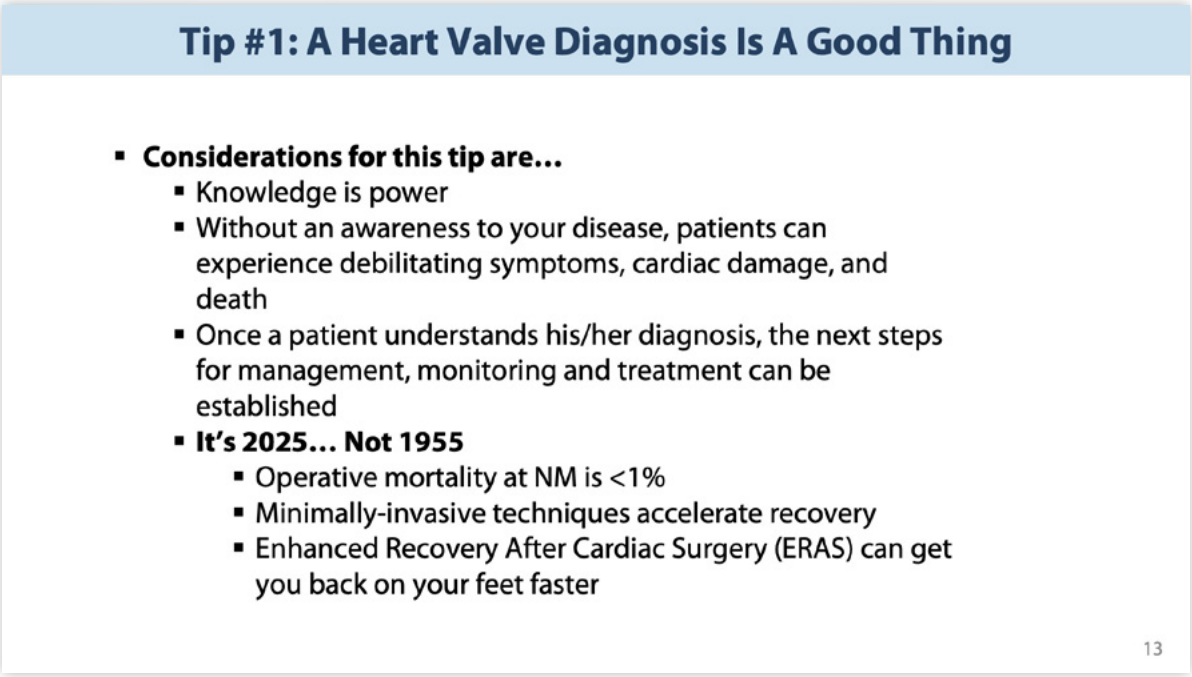
Adam Pick: The big point I want to make to you, whether you're diagnosed this morning or 15 years ago, you are not alone. There are teams, heart teams, all over the place that are waiting to help you. Today, for example, we have a team of cardiac surgeons. They work with all the folks that you see online here today, whether it's cardiologists, interventional cardiologists, valve clinic coordinators. There are teams in place to help you.

Counter-Intuitive Tip #1: A Heart Valve Disease Is A Good Thing and Can Save Your Life



Dr. Johnston: We're going to give you some tips that may be a little bit counterintuitive. We're going to tell you some things that insiders know about how to deal with heart valve disease. Think of this as just a high level framework for how you think about a diagnosis of valve disease or helping a family member or those kind of things. Let's dive into it.

Tip number one... Heart valve disease diagnosis is a good thing and can save your life. Why is it a good thing? It's a good thing to get a diagnosis. There are so many patients who have heart valve disease without knowing it, and how they get diagnosed can be often random. You may go to your primary care physician and they hear a murmur could be a family member that hears a murmur when they're giving you a hug. You might get an echocardiogram for a reason that is not related to the fact that you have valve disease or maybe something else going on, or you might have another test like a CT scan or an MRI that can show calcium on a valve. There are a lot of different ways, but knowing you have valve disease means that we as your heart team can help you track it and help you to get through right intervention when you need it.



I would say knowledge is power. If you're aware of your disease, you can avoid all the bad downstream. Things that can happen in terms of damage to your heart develop debilitating symptoms, and in some cases, and this is fortunately very unusual, sudden death from valve disease.

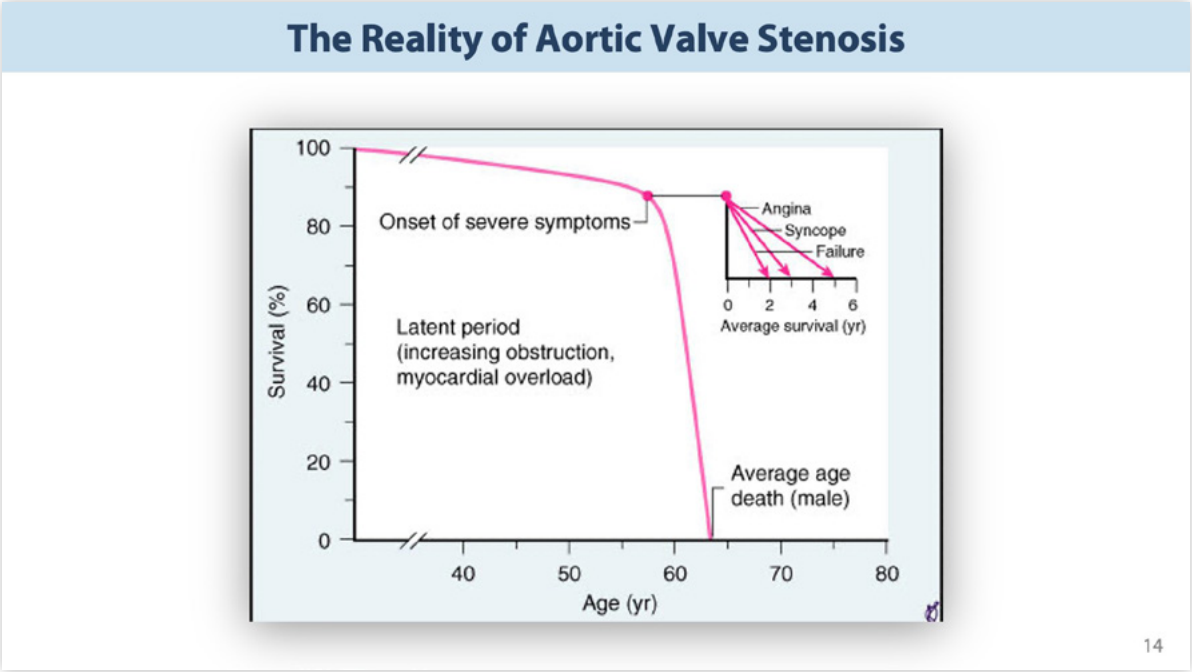
Once you know what you have, we can help you understand it. For many patients, it may just be an echo once a year to see how your valve is progressing.

It is 2025. It's not 1955. I asked some family members of mine what they thought the risk of dying from a heart operation was if they needed to have a heart operation that wasn't an emergency. The average number that I heard was 15%. This is including my mom who obviously knows that I'm a heart surgeon. I said, "Really, mom, you think that 15% of the time people come to my operating room and don't make it out?"

This is not 1955. Mortality at Northwestern Medicine for valve surgery in general is less than 1%. In many cases, it's much less than 1%. We have a number of ways to help you get better, including some of the minimally invasive techniques that we all focus on.

Dr. Hodges focuses on the robotic side. You'll hear from him. We can often help you get back up and running faster through what's called enhanced recovery after cardiac surgery or ERAS. We have a lot of ways to get you through this faster and in a way that will not be a major impediment to your life.

The Reality of Aortic Stenosis



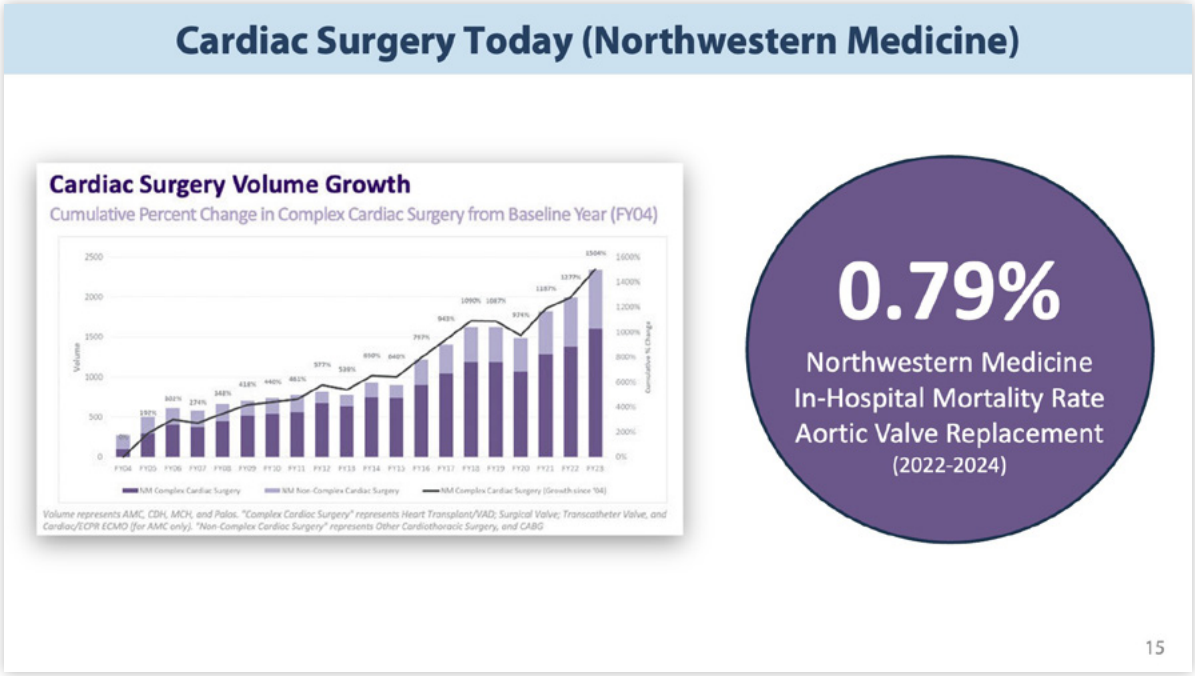
Dr. Johnston: This is a really great picture. This is a very old figure from a very famous paper by Dr. Braunwald, who's one of the most famous cardiologists in valve disease. Basically what it said is, if you have aortic stenosis and you are not intervened on, you don't have a valve replacement, that your survival, your likelihood to live after you develop symptoms which are severe, and fortunately today, most people don't get those, your survival is worse than most cancers.

Most people are dead within a few years if they don't get treated. Severe valve disease is a very lethal problem.

Now this dates back to the early 60s when there wasn't really good therapy for a lot of patients with severe valve disease, but this is what happens when we don't do anything about it.

Fortunately, as we said, we have a lot of good things we can do. Surgery is very safe. Transcatheter procedures for valve disease are advancing very quickly. We got a lot of tools we can bring to bear. You should not be the person who falls off the cliff here on the right side of the picture. We want you to be the person who is alive talking to your grandchildren about how you had a valve operation 50 years ago. I think that's what the situation that many of you will be in.

Cardiac Surgery Today: Growth and Outcomes



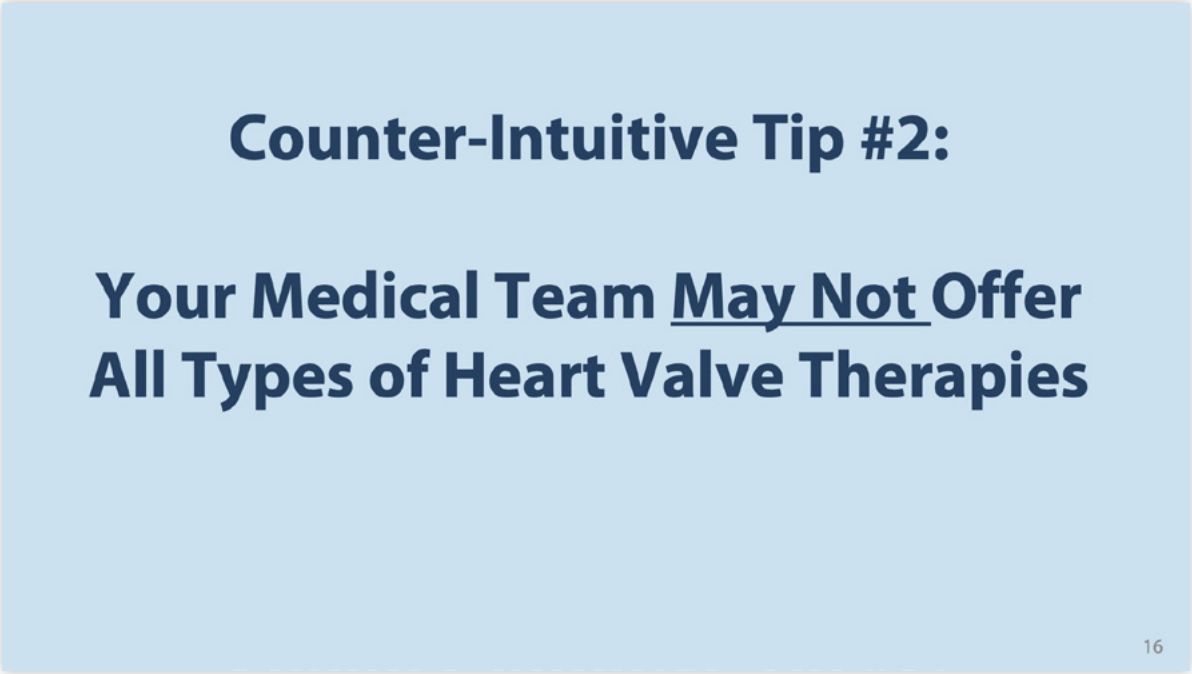
Dr. Johnston: At Northwestern Medicine, we are growing very fast in terms of the number of patients we take care of. Our mortality rate, as I said, for valve surgery with a lot of different ways to measure this, but one operation that people use to benchmark a valve program is what's the mortality rate for isolated aortic valve replacement? Nationally, it's about 2%. In our hospital, it is well under 1% and has been for the last several years.

As I said, we have a lot of different ways to do those operations, but many of the people who come to us for valve surgery are coming from far away because either they can't get the same quality. That's an important thing we'll talk about, asking about what the quality is of the center that you're talking to or they can't get the same type of procedures.

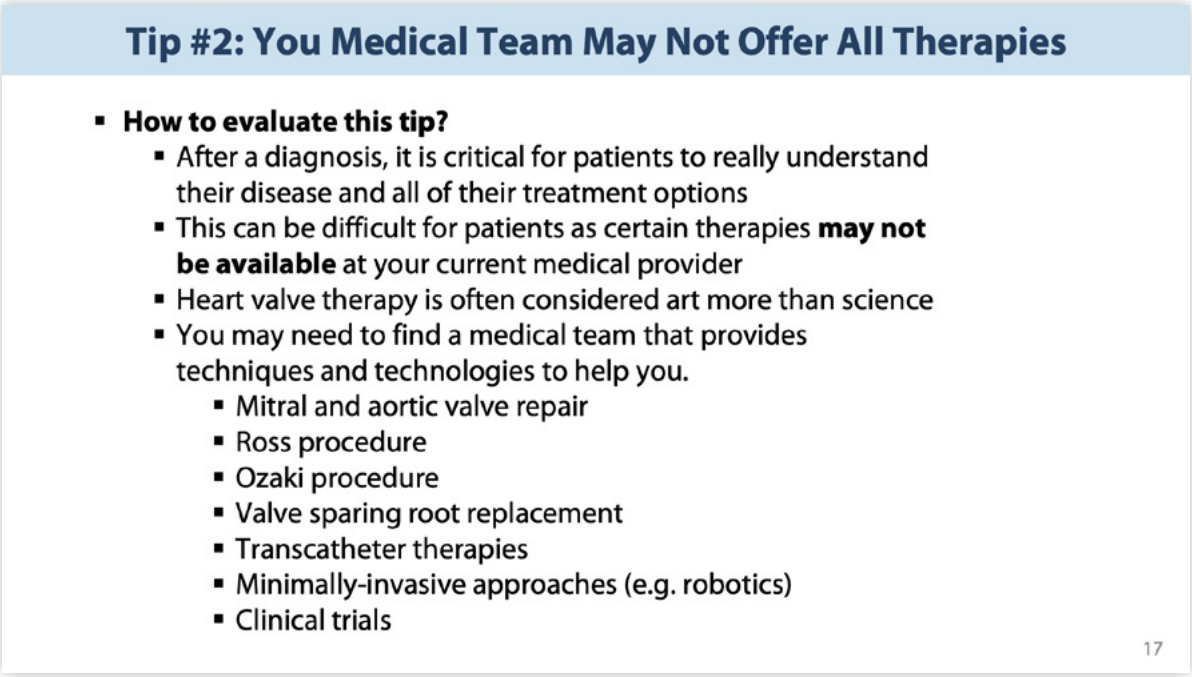
We're very happy to talk to patients from anywhere in the country. I spend most of my days - when I'm not in the operating room - doing telehealth visits with people from all over the place, often with very challenging cardiac problems, but sometimes there are people with a new diagnosis who just want to know what we can offer them surgically.

We're happy to see you even if you don't live right here in Chicago, and especially if you don't live right here in Chicago; if you're in Alaska, like Kevin, where one of my recent patients came from.

Counter-Intuitive Tip #2: Your Medical Team May Not Offer All Types of Heart Valve Therapies



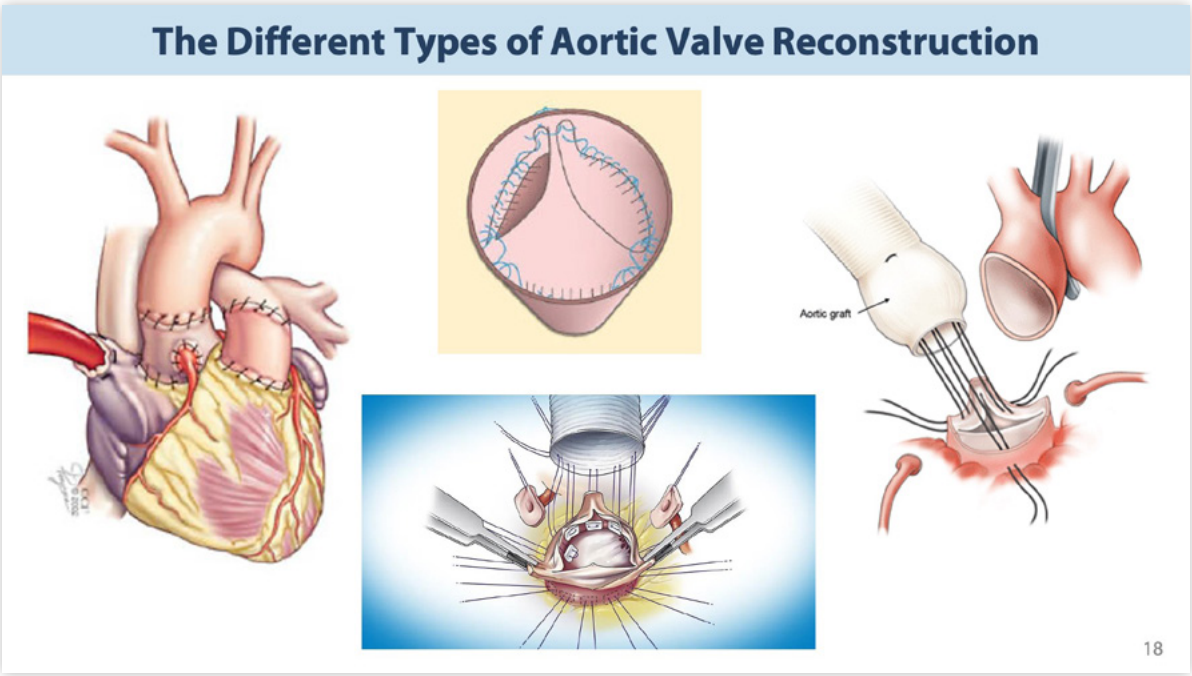
Dr. Medina: Thanks, Doug. That was great. You brought up a lot of really great talking points. I'm going to piggyback off some of that. The tip I'm going to talk about is your medical team may not offer all the type of heart valve therapies that is to be out there.



Okay, so I think we can all acknowledge that after being diagnosed with any issue with your heart, stressful diagnosis to have, but of course, it's extremely important for patients and you all to understand what's going on so you can make the best choice for you. It can be overwhelming, not only the thought of needing heart surgery itself, but sometimes having these various options open to you can be hard to navigate.

Especially at centers like at Northwestern and other big volume centers, the medical teams can help you consider the various types of options and figure out what factors and help you choose what's right for you.

Different Types of Aortic Valve Reconstruction



Dr. Medina: For example the treatment options for various valve pathologies can include, for root replacements, for example, traditional root replacements, rosses, valve sparing, root replacements, or even the Ozaki procedure for various approaches to valve pathologies. As Doug and Kevin are going to be alluding to, there's the minimally invasive approaches with small incisions on your chest versus using even smaller incisions that Kevin does with the robot. Also various transcatheter options that are there with MitraClips and TAVRs and various procedures that can be done with our interventional colleagues are also available.

I think, like I mentioned earlier, it's very important for all of these therapies to be at least explained to you and your families to figure out what's the best route that you can take. This is what I alluded to earlier. All of these surgeries can be offered here at Northwestern. The Ross Procedure here as well as the valve sparing are two of the very common operations that we can offer as well.

Adam Pick: If I could interrupt for just a quick second, I think I'm a great case study in this because when I was diagnosed with aortic stenosis and a bicuspid aortic valve, the first thing I was told was, well, you can get a cow valve or a pig valve or a mechanical valve, and that was it.

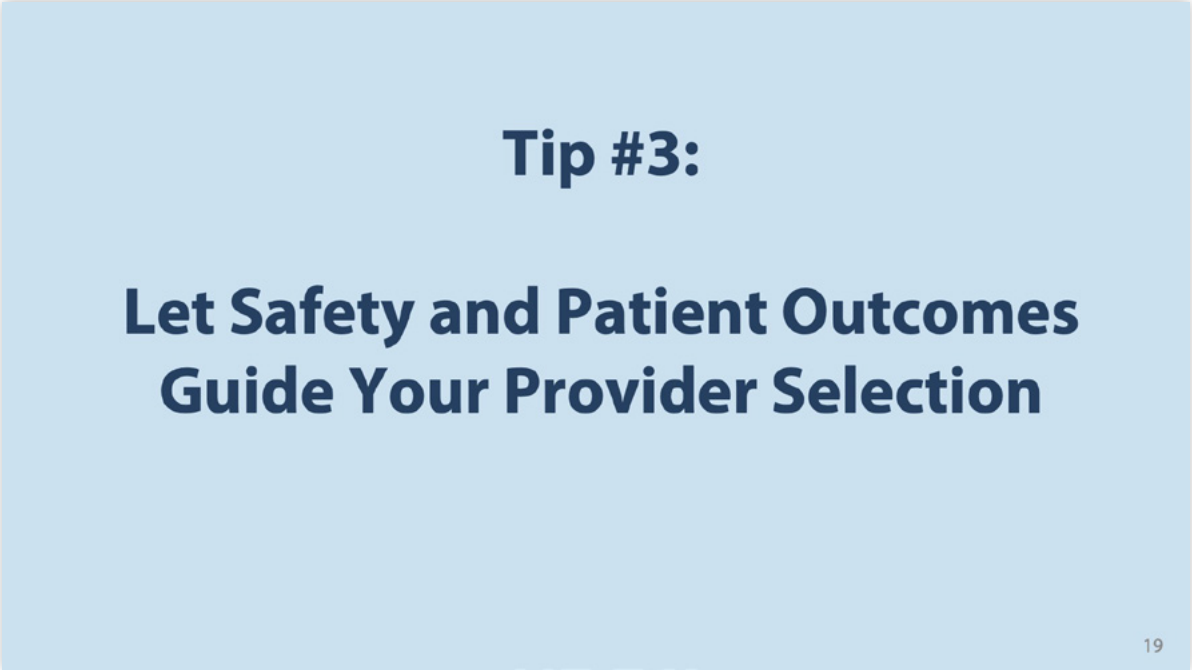
Dr. Medina: Yeah.

Adam Pick: Then I went ahead and I really did some research. I became my own best advocate to figure out if there wasn't another operation, and that's where I learned about the Ross Procedure, which I ended up having done. It's been 20 years now. I'm free from re-operation. I've had no intervention, and it's only because I went to a center that had that skillset for that specific procedure that I've had all these great benefits of durability without blood thinners. I'm curious to know when you have a patient come to you and say, hey, look, I've got aortic valve disease, for example, do you walk them through all of the different options that are available and explain to them why one may be more advantageous than the other?

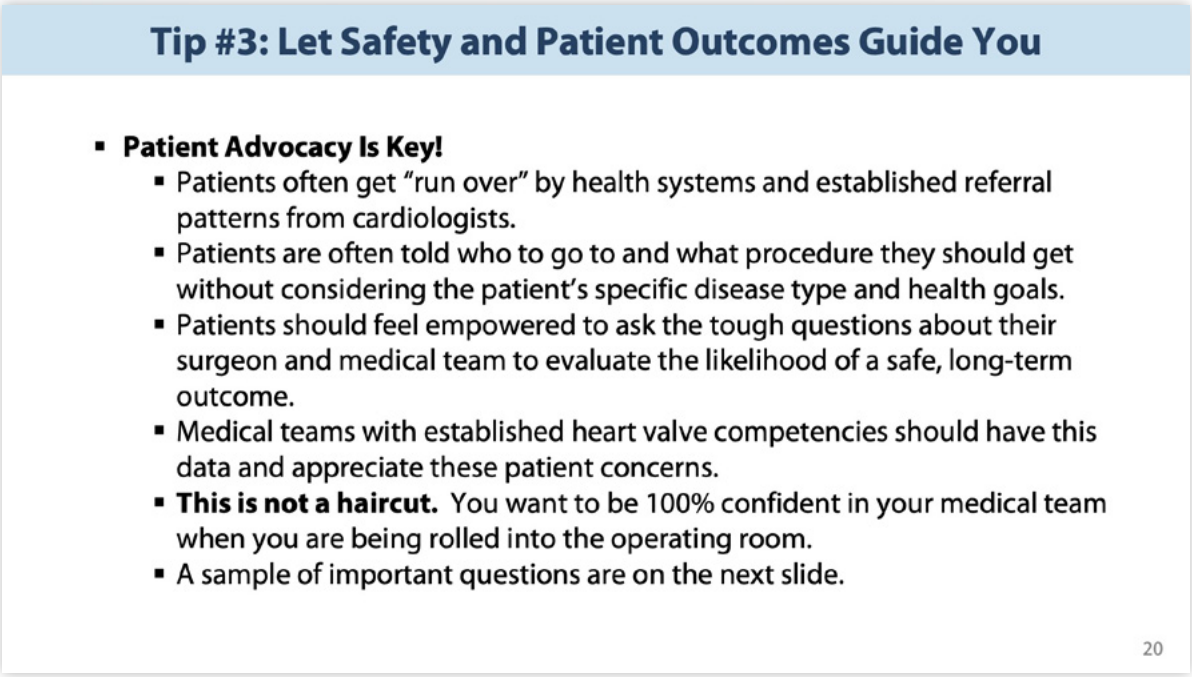
Dr. Medina: Adam, first, I applaud you for being your own advocate and finding a center that can best serve you. To your point, absolutely, whenever I see a patient in clinic who is in need of any valve intervention, I think first of all, you know what their comorbidities are and their lifestyle especially and to see what we can offer them, whether that be transcatheter versus if they're young, we can offer various procedures such as the Ross. We're high volume center for these complex cases as well.

Adam Pick: That is a great point. I just wanted to make sure the patients really understand how this truly feels like it's the "golden age" of valve therapy. There's so many different options and let's keep going on. Thanks so much. Let's go over to Dr. Hodges for tip number three. Thank you.

Tip #3: Let Safety & Patient Outcomes Guide Your Provider Selection



Dr. Hodges: This tip is all about empowering patients to make the right decisions for their treatment. The tip is let safety and patient outcomes guide your provider selection.



Patient advocacy is key, and the first point here says, patients often get run over by health systems and establish referral patterns for cardiologists. What that means is that really there are a number of factors that influence how referrals are made for important interventions like heart valve surgery.

Those things might be referring provider's opinions about what is the right procedure. It may be opinions about who is the right provider to do that. It may be that they have established relationship within a large health system where they're encouraged to refer locally.

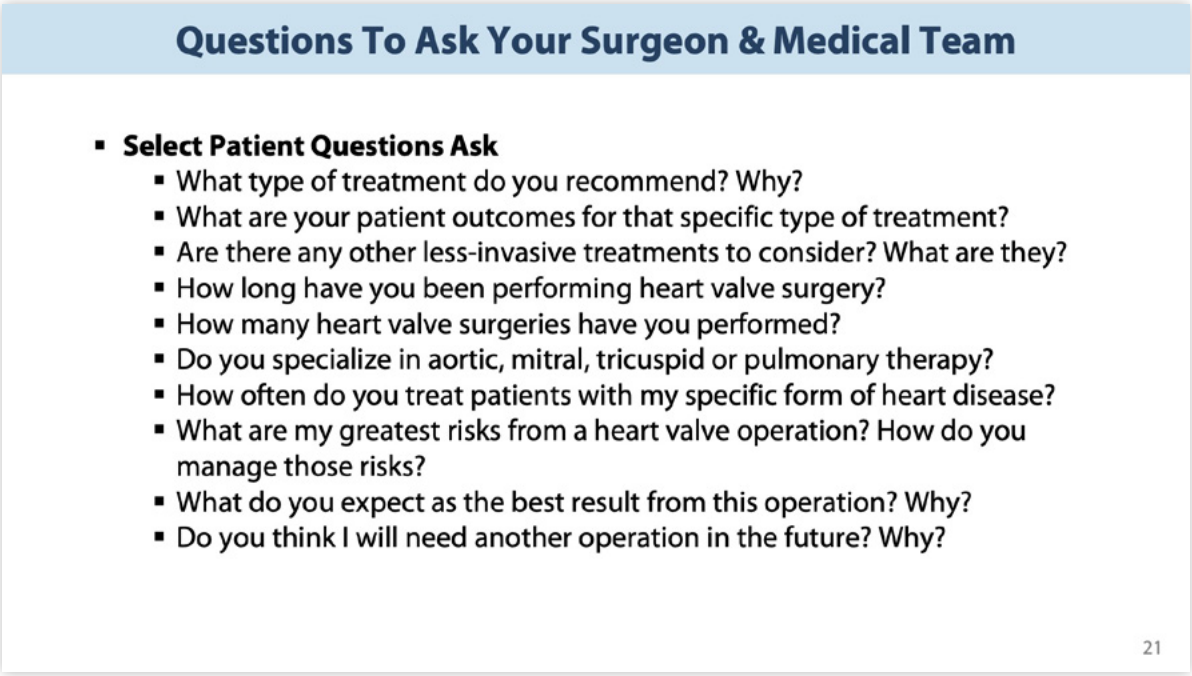
There's a number of things that go into this, but ultimately what matters most is that patients get the right option for them. What that means is that patients should feel empowered not just to get opinions from their cardiologists or their primary care doctors, who they rightly trust very much, but to seek second opinions and to use resources like HeartValveSurgery.com to understand

the range of options available both in terms of providers, center type and procedures.

I think this comment at the end, this is not a haircut, is really important. I mean, this is often the biggest medical procedure that a patient will have in their life and one of the most consequential things that will ever happen to them. You need to make sure not just that you're making the right choice, but that you're confident in your medical team.

I think about this a lot that making a decision about what procedure to have or what surgeon to choose is difficult. There's not any one way to know what is the right choice, but I would say there are resources like the STS database, that's the Society of Thoracic Surgeons, that ranks centers on quality. There are all of the news rankings like US News World Report, and then there are rate resources like heartvalvesurgery.com that know all of us very well and help direct you in some objective way to the right choice.

Questions to Ask Your Surgeon



Dr. Hodges: We have a list of some sample questions so that when you as a patient are seeing a provider to discuss your heart valve intervention, you can think of these things as good ways to go. I would emphasize that, especially at a place like Northwestern where we see a lot of patients and second opinions, there's no question that's out of bounds. We want patients to ask questions.

We want them to ask what often they perceive as tough questions. We welcome that because it allows us to make sure that we're both on the same page. One easy one is what type of treatment do you recommend and why. I see a lot of patients with mitral valve disease and sometimes patients have heard that certain valves should be replaced rather than repaired. Often I have a very strong feeling in the other direction. If a patient comes to me and says, this valve must be replaced, I've heard that from X, Y, or Z, I tell them or I feel very strongly that this is a valve repair situation. Other situations like an aortic valve disease, we go through a number of options and discuss what might be the right specific

procedure for a given patient.

It's fair to ask what are the patient outcomes for this specific treatment; not just big pictures, but specifically in patients who have had a valve repair or a Ross or Ozaki, how are your patients doing? Are there less invasive treatments to consider? In mitral space, there's transcatheter edge to edge repair. People have heard the term MitraClip which is an emerging technology that we're still learning more about in our practice. We feel it's not right for everybody, but it's a great tool for some, and it's important to talk through these things and to make sure patients know the range of options, even if it may not be the right choice. How long have you performed heart surgery? How many heart valve operations have you done?

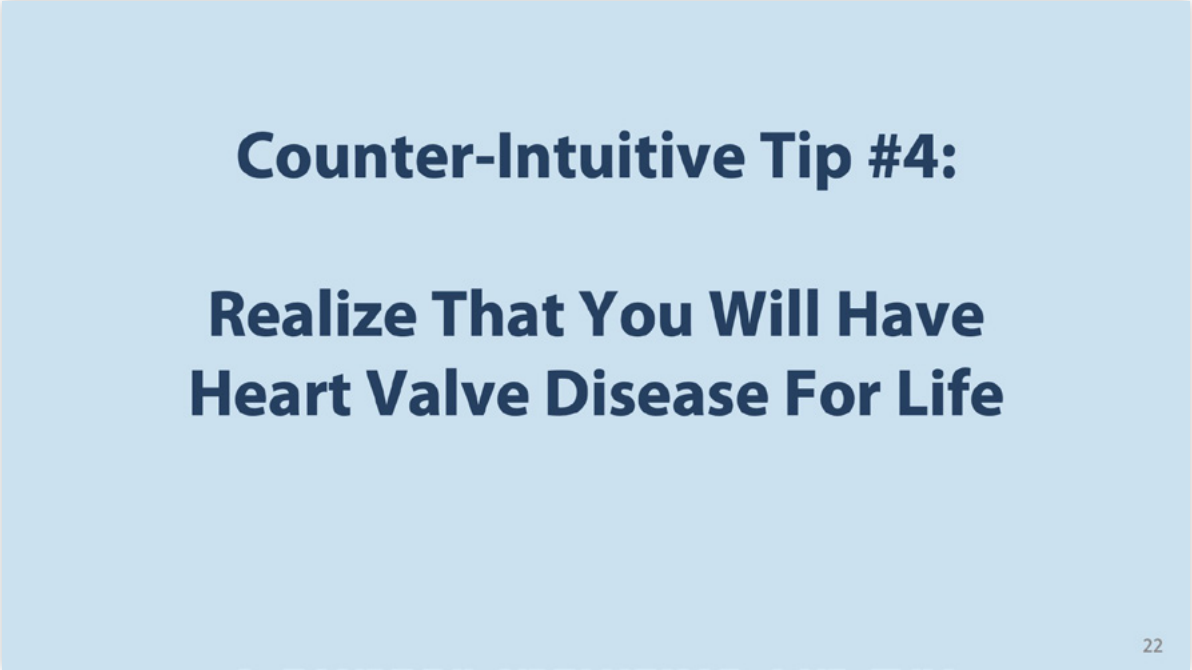
People shouldn't shy away from that. Even if they're a relatively inexperienced surgeon, they should give an objective, a picture of their practice, their training, and why they feel that they can do a great job for you. This next one I think is really great. Do you specialize in aortic, mitral, tricuspid or pulmonary surgery? Just because a surgeon may be extremely famous, they may be at an extremely famous center, doesn't mean that they're the right surgeon for a particular problem. I think it's important to ask your surgeon, do you specialize in the exact problem that I have?

Do you treat patients with my specific form of heart disease is essentially the same. What are the greatest risks? I always say people are worried about death, stroke, and dialysis, but there's a lot of different risks and a lot of different considerations, and to talk through the specific nuance concerns for each operation, I think is essential.

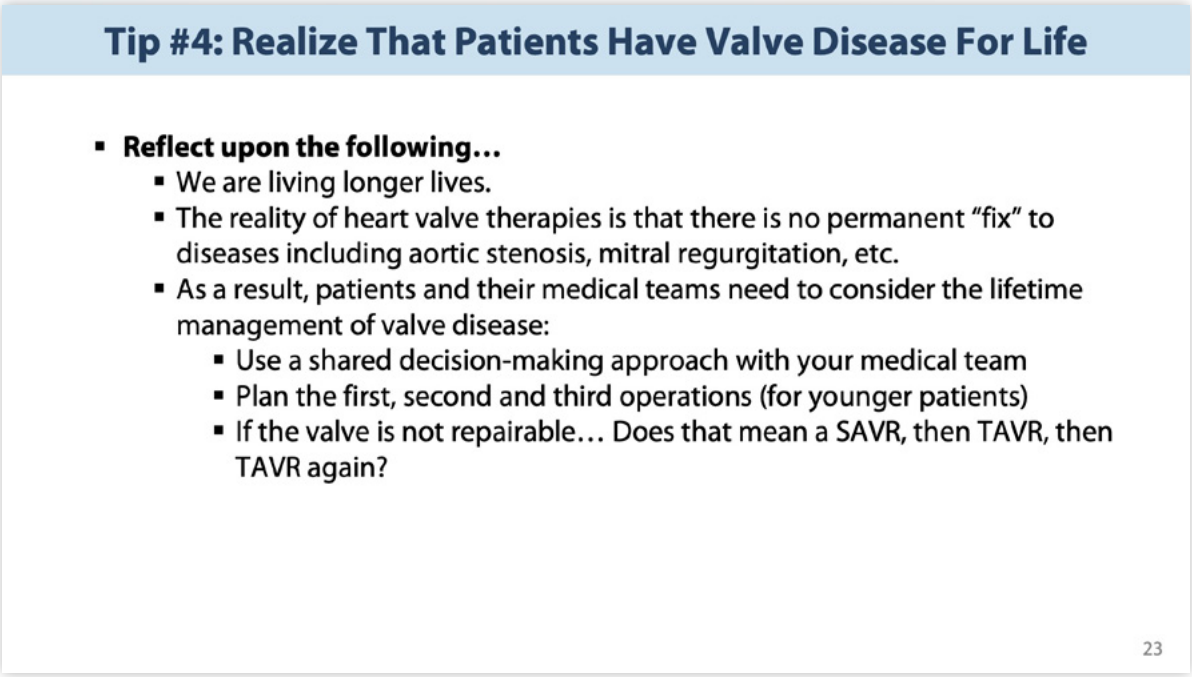
What do you expect as the best result in this operation? I think what do you expect is the worst result from this operation, because I think the vast majority of cases, the best result is the same. It's a return to totally normal quality of life, it's an improvement or elimination of symptoms, and ideally a good durable result that's thought out for an individual patient, but that's not true of everybody. I think that has to do with where people start, what are their risk factors or other medical problems, and I think having a really clear picture of what you're getting into is super important.

Then the last one is, do you think I will need another operation in the future? Adam, you alluded to this with your Ross Procedure that you've now been 20 years without an intervention, which is a fantastic result. I think everything's a little bit different and understanding the likelihood of needing something else in the future is important to set expectations in the future. The point of this one again be willing to ask questions. No provider, no surgeon should ever be offended by your questions or put off by that. I think that's a big red flag. We're here to answer your questions. We're here to give second opinions when called upon, and we are all here to encourage you to get as many opinions as you need to be comfortable with the decisions that you make for your own care.

Counter-Intuitive Tip #4: Realize That You Will Have Heart Valve Disease For Life



Dr. Johnston: Counterintuitive tip number four… Realize that you will have heart valve disease for life. This is a tough one. I'm not sure I like the term heart valve disease, because for many patients, and you heard Adam's story, you have a heart valve issue, you have a heart valve – I don't know what's the best thing you have to think about. For many patients who have a successful procedure for their heart valve disease or are earlier in the stage of disease, basically what it means is you're going to have a lot of years of a normal life where you might need an appointment once a year to get an echocardiogram. That's really a pretty good thing to have going on with your heart. There are types of heart disease that are very serious, that have implications about your life expectancy and those kind of things. Many patients with heart valve disease can live a normal life expectancy and totally normal lifestyle. While you will have to think about your heart valve for your life, it may not be something that you would really think of as disease.



Why is this important? We are all living longer lives, life expectancy and the expectation of having a very active life is increasing. We have lots of patients in their 70s, 80s, even 90s, who are very active people and where it's not just the life expectancy, but it's the quality of life that matters. I operated on a 94-year-old gentleman who was a very active pickleball player and had a bad mitral valve problem last year. You might think, why are you operating on somebody who's 94? He wanted to get back to playing his level of pickleball, and he was otherwise a hundred percent healthy. That's a fixable problem in somebody who has probably many more years of life.

While lots of things we can do for the heart are not permanent, many of the things we can do like valve repairs, like the Ross procedure, like tissue valve replacements and even mechanical valves, while the machine itself may last a human lifetime, they can stop working for a number of reasons. In general, these fixes are very durable while they may not be permanent. If they do fail in the future, we have lots of options to treat them that are also very safe.

The reason we talk about having valve disease for life is it means when you have a procedure, it doesn't mean you're done. We want you to have a relationship with a physician or team. It doesn't necessarily even have to be a cardiologist. Some patients that I've operated on have excellent PCPs and they get the patient in for their testing every year. You need to have regular surveillance of your valve and you need to have people that you trust when there's a change. Many patients have asked us questions about findings on an echo or other study. It's important that the people you go to are not, to Kevin's point, one trick pony. You don't want to hear this is the only thing we can do for you. What you want to hear is here are the options, here are the relative risks and benefits, and how does this fit in with what you want? That's the first question I ask my patients. What do you want to get out of this? Shared decision making means you are the center of that decision.

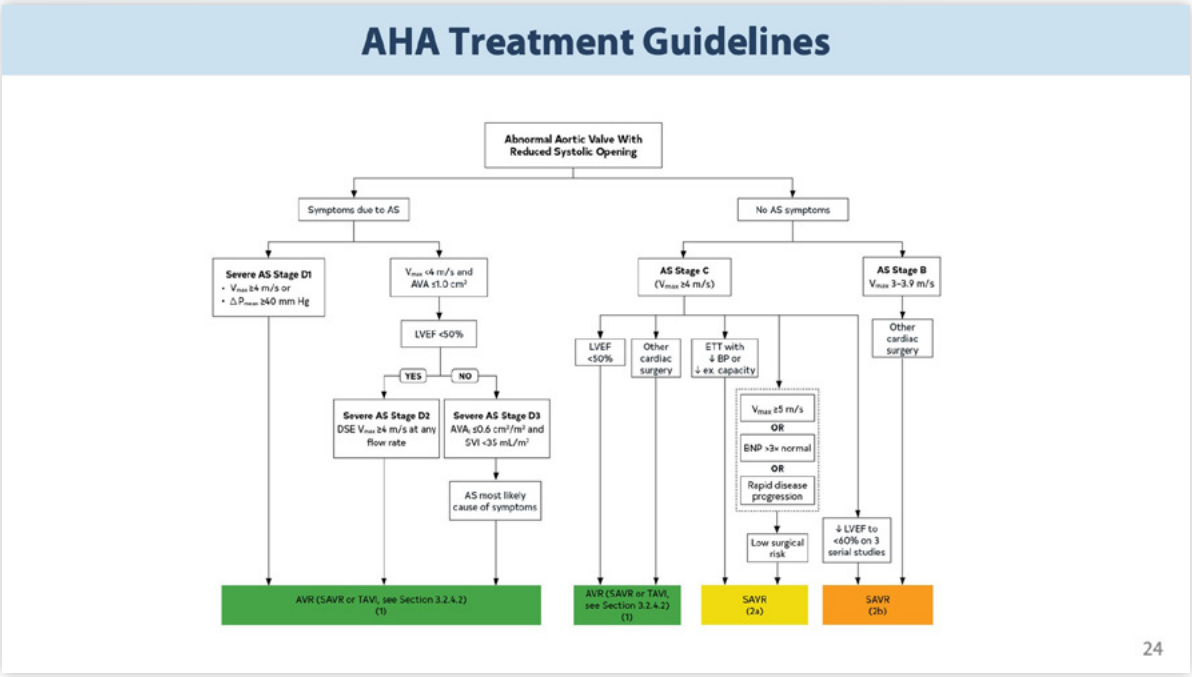
If you're young, and young these days can be a lot older than we used to think, you might need a second or a third procedure of some sort in your life. You might have a totally normal lifestyle in between those procedures, but it's important that we plan for what the options are. We want to think about the fact that technology is going to change a lot in the next couple decades of your life. We don't want to pigeonhole ourselves into only one option. Having this conversation of what happens next is very important.

Adam Pick: Dr. Johnston, I love the story about the 94-year-old patient wanting to continue playing pickleball. I'm sure patients on the line are wondering, as I plan for this lifetime management of the disease, I'm curious, you've done

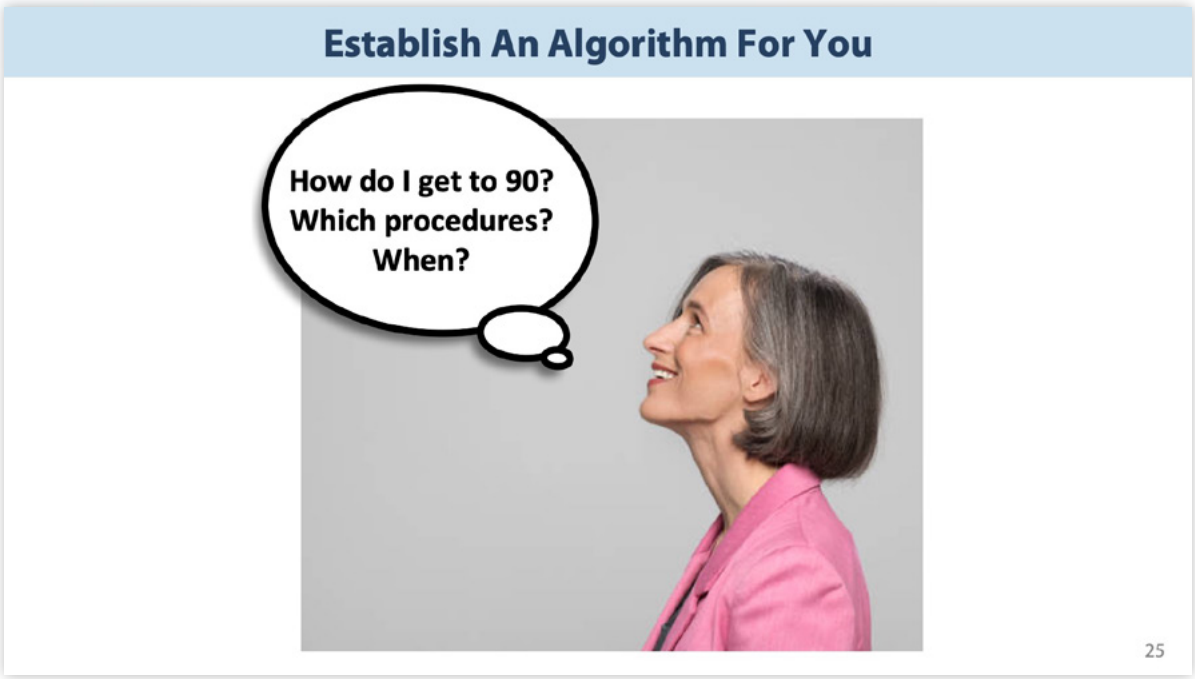
thousands of heart valve operations, what is the most amount of valve therapies that you've done for one patient, if you can remember?

Dr. Johnston: It wasn't all me, but I'll tell you two interesting ones. I operated on a lady who was in her 80s who had an atrial septal defect repair by Dr. Kirkland when she was 15 years old. We operated on her more than 60 or almost 70 years after her first operation. That was the longest distance, longest interval between two operations that I'm aware of. We did a double valve replacement and she did very well. I've done an eighth time operation on a patient. The first operations were certainly not all done by me, but somebody who had their first operation in childhood, and that's the most in my experience. There probably have been people who've had more, but it's just a testament to the fact that people can get through multiple interventions in their life and our job is to try to make the distance between those interventions as far as possible. We're not saying we want to give you a lot of surgery, but if it keeps you doing what you're doing, if it gets you back to the life that you want to live, we have a lot of options to re-intervene when things go wrong.

Adam Pick: Great, thanks so much.



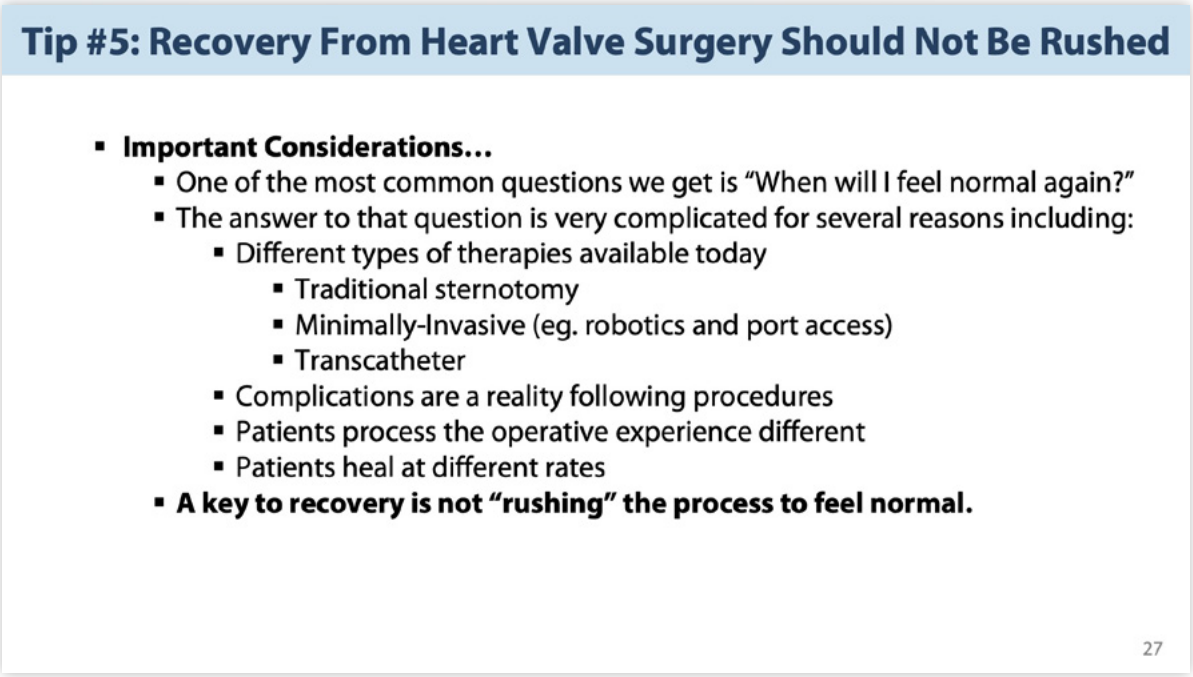
Dr. Johnston: This is an eye chart. We'll have this in the slides for you folks to look at after the webinar, but just to look at how we think about a decision tree for patients who have a particular type of valve disease. There are a lot of criteria here. I think the main reason to put this in here is so you recognize the fact if somebody tells you, you have a tight valve, you need an operation, it's never that simple. There are a lot of factors that we look at, including who are you as a patient, how old are you, how active, what else is going on with your heart that go into the decision making. There's a lot of evidence. This green, yellow, red is based on the evidence that people will do better versus the evidence that people will do worse. At a very minimum, your team should be able to explain to you how they're using guidelines like this to help make decisions in your care.



How do I get to 90? Play a lot of pickleball, I guess this is the answer, but this is a question you should be talking about with your team.

Counter-Intuitive Tip #5: Recovery From Heart Valve Surgery Should Not Be Rushed

Dr. Medina: The recovery from heart valve surgery should not be rushed. I think between all of us, we get this question a lot, how long do I expect to stay in the hospital? How long should I take off work? How long do I refrain or how long can I start playing pickleball again or the activities that make you happy? I think we could all acknowledge that normal can have a very different meaning for all of us and for different people. It's difficult not to compare what you're about to have done to what your neighbor had or what your friend had or what your uncle went through when they had their bypass surgery or valve surgery.



I think something important to keep in mind is that people recover in different ways and taking various amounts of time. Something also to take into consideration is how sick you are going into surgery and what symptoms you were feeling leading up to it. Everybody's expectations are always going to be a little bit different. We talked about the different approaches to valve surgery. Given how far our specialty has come over the years, as we've said before, we can offer many options, but that also means that each option or therapy, whether that be undergoing something minimally invasive with small incision or a small puncture site in your groin versus a traditional incision with a sternotomy, each can have various recovery times.

Regardless of the approach though I think heart surgery is heart surgery and complications are an inherent reality. A good mindset, at least what I tell my patients is forward progress is a positive and not rushing to feel "normal" is just something to be aware of, and because it does vary from person to person, it's different for all of us. It's important to listen to yourself. I encourage all of our patients to walk after surgery, but obviously if you're tired, take a break, but each day progress, walking more and more distances. I think forward progress is a great mindset to have after surgery.

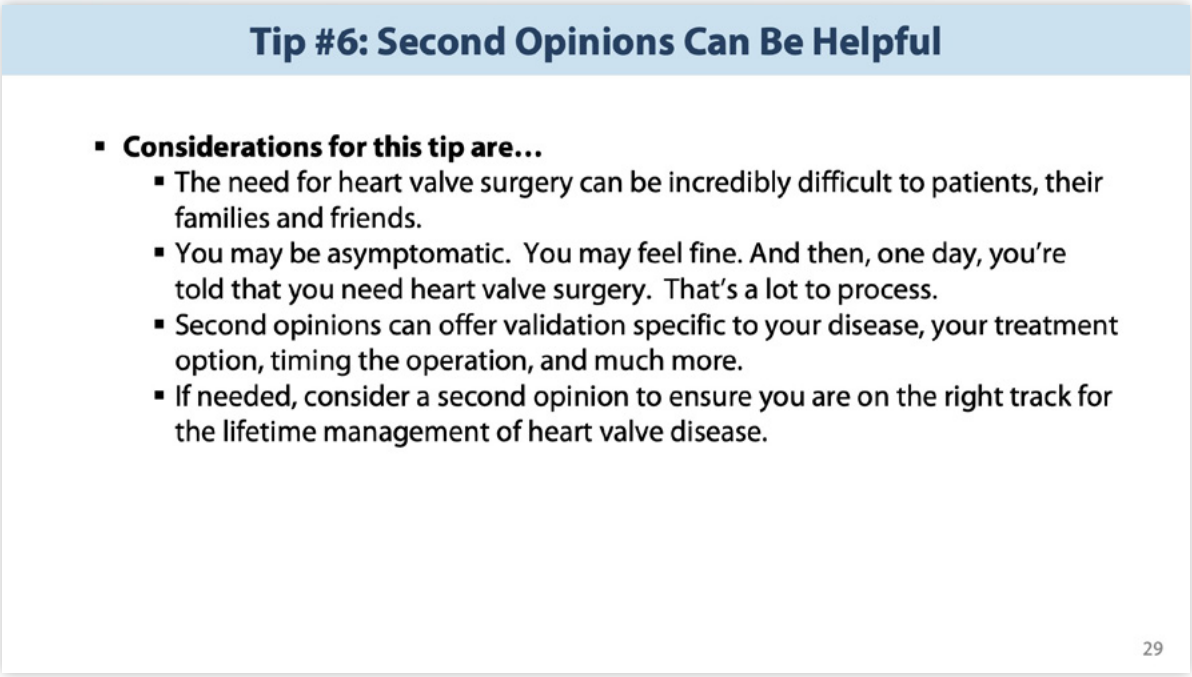
Adam Pick: Dr. Medina, for the patients who may be just recently diagnosed, or maybe have been in the waiting room for some time or getting ready to go into surgery tomorrow, you mentioned that complications are a reality following these procedures. Can you maybe talk about what some of those complications may be and their prevalence?

Dr. Medina: I think with any operation, not only heart surgery, inherent to any operation is a risk of infection. There's of course bleeding. Me, Doug, having healthy individuals undergoing heart surgery, we have the inherent risk just being put on the bypass machine for renal failure or strokes, all very minimal risks, but they're there nonetheless. I think it's important to discuss those with our patients and just have the overall picture so that they know what to expect going into surgery.

Adam Pick: Thank you for setting that expectation because I often get emails from patients that are a complete wreck as they've had a complication, whether it's atrial fibrillation or something else, and they feel like they've done something wrong, and that's just not the situation. This is just a part of cardiac surgery or any surgery for that matter.

Tip #6: Second Opinions Can Be Very Helpful for Patients

Dr. Hodges: I really appreciate that last tip from Melissa. I think a lot of the things you mentioned, AFib, things like fluid accumulation, maybe needing to even have a fluid drain from around your lung or something are perceived sometimes by patients as big setbacks or signs that things aren't going well, and I think it's something that we can occasionally do better as surgeons, is to prepare people for those things that can sometimes be a part of a very successful procedure and part of progress. Thank you for adding that. My tip is that second opinions can be very helpful for patients.



This ties back a little bit to my last one, but I think second opinions are essential. The need for heart surgery and the decision about this can be very difficult for patients to process, for their family and friends to process. It can feel like a lot is being thrown at you at once. Especially if you're asymptomatic, to the second point, you may feel totally normal and suddenly a physician is telling you that you need to have open heart surgery and it can feel like the world is crashing down. Sometimes getting multiple opinions, even if you get an opinion from two providers that say exactly the same thing, can help you to really settle into what's going on, to the very first point that Doug made.

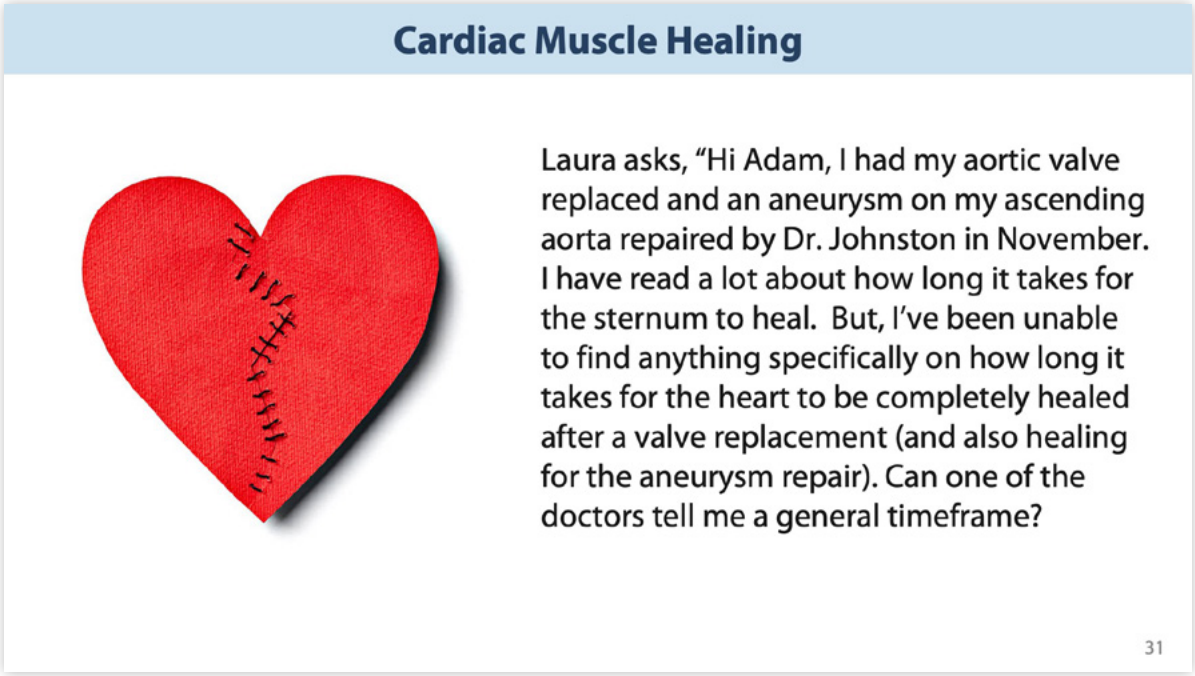
Getting these diagnoses sometimes feels like this sort of, why me, how could this have happened. Patients with valve surgery often don't have the same risk factors as say, a coronary patient. That's not because you smoked; it's not because you lived unhealthy lifestyle. It's often a genetic thing. It's the way you were born, but to understand that this is an important diagnosis that's made. There's so many options that can get people back to normal often with minimal risk. Often just hearing this from multiple providers who ideally are all encouraging and talking through the process, I think can be very valuable. That's to the validation point. To the last one, I think is really why people get second opinions most of the time is consider a second opinion to ensure you're on the right track for the management of your issue. I think we've hit throughout this webinar on the issue that for any given valve problem, there are a number of treatment options.

Providers, whether they be surgeons or cardiologists, may be biased in favor of one or the other. I think everybody in our field universally, I may be a little bit of an optimist, but I think that everybody is looking out for patients. If they give you one procedure over another, it's out of that motivation. The reality is that there's often a lot of things. You don't always get the whole picture from one person or one institution, and seeking multiple opinions can really help you understand what your problem is, what the options are, and what the path forward will be. I encourage any patient to seek a second opinion. We at Northwestern are always happy to provide that. Even if you come right out and say you're going to stay with your other surgeon, that's fine. We're here to provide you that validation or maybe give you a little information you didn't have before. We're always happy when our patients seek second opinions about what we've told them. It's all about patient empowerment and making an informed decision that you're happy and comfortable with moving forward.

Adam Pick: Dr. Hodges and for the folks on the line, what you just talked about was my exact experience regarding second opinions. I felt like I had done something wrong. I felt like my world was crashing down on me. I didn't know what to do, who to trust on the front end. I didn't know what procedure to have.

It wasn't until I got the second opinion that I realized it validated the first opinion, and that's when I got a certain amount of calmness over what would be next for me in terms of taking care of my valvular disease. Thanks so much for putting it together about second opinions.

Questions and Answers



Adam Pick: Let's start the Q&A section of the webinar. This is a fascinating one because it comes in from Laura. Dr. Johnston, just so you know, this is your patient. She asks, "Hi Adam, I had my aortic valve replaced and an aneurysm on my ascending aorta repaired by Dr. Johnston just in November. I've read a lot about how long it takes for the sternum to heal, but I've been unable to find anything specifically on how long it takes for the heart to be completely healed after a heart valve replacement. Can one of the doctors tell me a general timeframe?"

Dr. Johnston: Laura, great to hear from you. Maybe we should have had this conversation before surgery. I'm sorry that I didn't talk about the heart itself healing, but in general, the amazing thing about heart surgery is your heart has to work pretty normally right away after the operation. As far as most things that people would go back to doing, like exercise, as you probably know, we recommend going back to aerobic exercise as soon as you can do it after surgery. The things that we might be concerned about for an aneurysm, so increased pressure on the aorta, are the same things we'd be concerned about with your sternum.

For a sternotomy procedure, we'd say no heavy lifting for six weeks. Six weeks is a timeframe when everything that's healing is likely to be about 85, 90% of normal strength, and so that's why it's okay to go back to normal activity. Truthfully, I've never heard of a situation where someone exercising or doing something like that caused a problem with healing of the heart. The heart is amazingly fast at healing even a big operation like an aneurysm repair. It's very quick after the surgery.

Heart Valve Replacement Durability

Sherri asks, "Hi Adam, I had a bicuspid aortic valve replacement with an Inspiris Resilia in the summer of 2023. When I had my check-up last fall, they said that the leaflets appear to be mildly thickened. There is also a mild leakage of the new valve. Is this common or normal to have such a thing happen in this short amount of time after surgery?"

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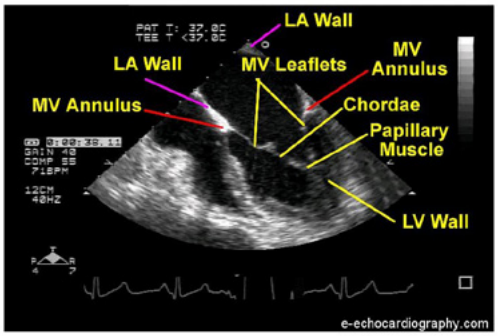
Adam Pick: Great, let's move on to Sherry's question about heart valve replacement durability. She says, "Hi Adam, I had a bicuspid aortic valve replacement with an Inspiris Resilia, that's a tissue valve made by Edwards Lifesciences, in the summer of 2023. When I had my checkup last fall, they said that the leaflets appear to be mildly thickened. There is also a mild leakage of the new valve. Is this common or normal to have such a thing happen in the short amount of time after surgery?"

Dr. Hodges: I can jump on, on that one. It's not happening more necessarily, but I think we're becoming more aware of this. It started actually with TAVR valves, some of these leaflet thickening phenomenon after bioprosthetic aortic valve replacement. We are starting to understand it more and more. In some cases, this has to do with what we call subclinical or not enough to cause serious valve dysfunction, but still there are thrombosis of the aortic valve. If that's what's suspected, oftentimes a short treatment with a blood thinner can be indicated or just monitoring depending on the severity of the situation and other factors involved. I think it's something we're seeing more and more, and it's often seen as alarming, but very rarely does this lead to a need for a re-intervention. I think it's a good thing to have a conversation with your cardiologist about, but I think it's fairly unlikely that it will lead to redo aortic valve replacement in the near future. I think we got a lot of options before that.

Conflicting Cardiologist Recommendations



Eileen asks, "For my mitral valve, I have 2 cardiologists and I've just recently been told by one of them to go to my surgeon and have a catheterization because of recent results of an echocardiogram. However, my other expert who is a seasoned and highly skilled cardiologist explained to me why he feels I should continue my "watch and wait" protocol. I have no symptoms and I'm energetic. I don't want to compromise my longevity. What should I do?"

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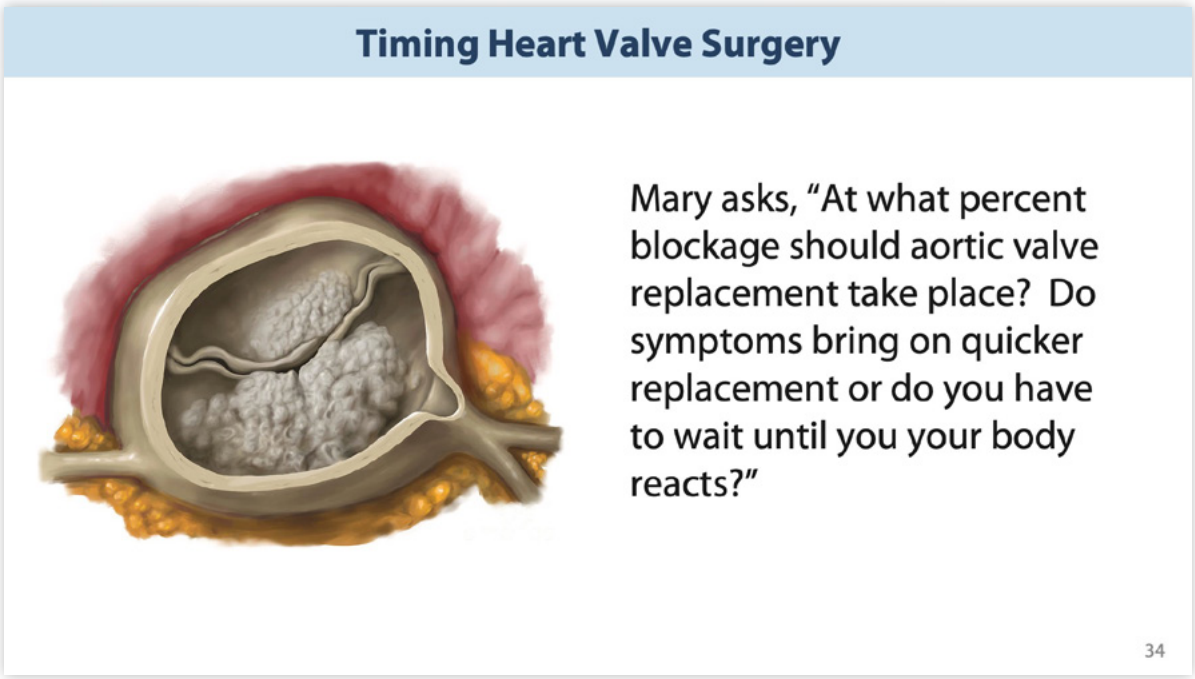
Adam Pick: Great. Here's a question from Eileen, and it gets back to what we've already talked about is conflicting information for patients. She says, "For my mitral valve, I've had two cardiologists, and I've just recently been told one of them to go to my surgeon and have a catheterization because of recent results of an echo. However, my other expert, who is a seasoned and highly skilled cardiologist, explained to me why he feels I should continue to watch and wait. I have no symptoms and I'm energetic. I don't want to compromise my longevity. What should I do?"

Dr. Medina: I can start with that one and then I'll let Kevin, the mitral expert, chime in with his two thoughts here. I think a lot of it, Eileen, probably has to do with what they're seeing on the initial echos and what the pathology of your mitral valve is. If they're seeing a change in your echo, there are certain echo criteria, certain measurements that we look at that even if you're asymptomatic we want to make sure it doesn't get worse. Kevin, if you want to add in, please do, but I think if you're asymptomatic and you say you're energetic, they may be seeing certain criteria that you might be meeting on your echoes that lead them to want to check out other aspects of your heart, like your coronaries that make you need a cath.

Dr. Hodges: Yeah, I'm not sure exactly what the pathology and question is, but if this were, for instance, mitral valve prolapse and a leaky mitral valve from that issue, we get this scenario all the time in our clinic. I think what a lot of it comes from is historically 10, 20 years ago, the approach to mitral valve regurgitation from prolapse was to watch this with serial echocardiograms until we saw signs of left ventricular dysfunction or if the patients develop symptoms. Based on a lot of data over the last several years, there's been a big move over the last five years or so towards earlier intervention. Valves can be repaired and when that repair is durable, patients often have a better result by being proactive about their severe mitral valve dysfunction to prevent bad things like heart failure, atrial fibrillation, pulmonary hypertension, or other complications that may arise if you wait too long and may prevent patients from going back to a normal life trajectory. Often early intervention is appropriate, but it all depends on the specifics of the situation.

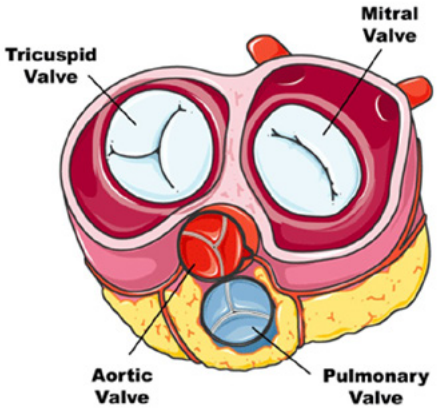


Adam Pick: Here's a question about timing heart valve surgery. Mary asks, "At what percent blockage should aortic valve replacement take place? Do symptoms bring on quicker replacement or do you have to wait until your body reacts?"

Dr. Johnston: I'll take a swing at that one. To echo what Kevin just said, the old school thinking about any valve disease was almost no matter how bad the valve looks on echo, we should wait until the heart starts to fail or the patient gets symptomatic to operate. That is definitely no longer true. Let's just debunk that whole theory. You may hear this from, in particular, older physicians who trained in the 80s and 90s. That thought process made a lot of sense in the era when heart surgery was much riskier. There was a time when having an open heart operation did carry a risk of mortality of like 10% for healthy people. That's a long time ago now. The risk benefit ratio was different, but we know now that for almost any type of valve disease, if the narrowing or stenosis or the leak or regurgitation is severe, that most patients do better if they have an operation before they become symptomatic.

As Melissa said, there's some echo criteria we can look at that aren't as rough as just is the heart failing that will tell us at what point a patient might benefit from an earlier operation. In general, for people who are otherwise in decent shape, it's the echo that ought to guide us before patients really feel short of breath or they're passing out or get dizzy or chest pain. Long story short, don't wait until your body reacts, talk to a valve expert and make sure you've got good imaging.

Multiple Types of Heart Valve Disease



David asks, "I am a 72 and was diagnosed with a BAV 10 years ago. Annual echos since then have not shown it to need attention. However, this year my echo identified a problem with the anterior leaflet in my mitral valve causing severe regurgitation. I am asymptomatic. The current thought from my cardiologist is to repair mitral valve and surgically replace BAV with a tissue valve during an open heart procedure. Any thoughts on my condition or possible procedures?"

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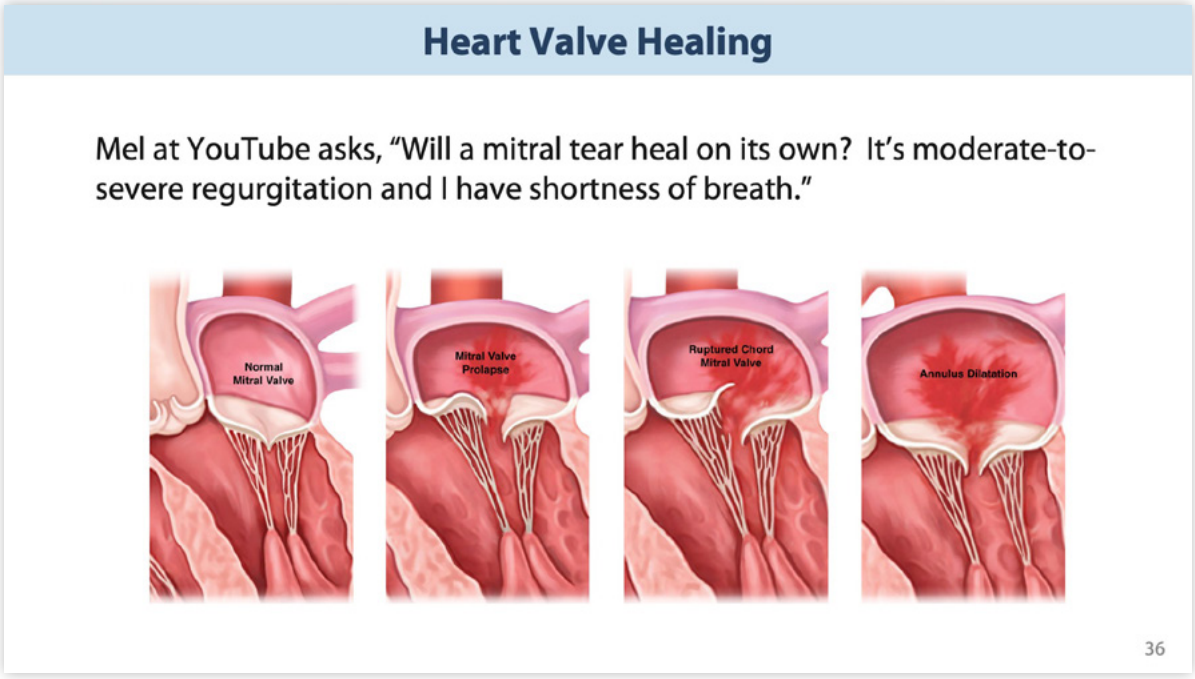
Adam Pick: David says, "I'm 72 and was diagnosed with bicuspid aortic valve 10 years ago. Annual echo since then, have not shown it to need attention. However, this year my echo identified a problem with the anterior leaflet in my mitral valve causing severe regurgitation. I am asymptomatic, the current thought from my cardiologist is to repair mitral valve and surgically replace a bicuspid aortic valve with a tissue valve during an open procedure. Any thoughts on my condition or possible procedures?"

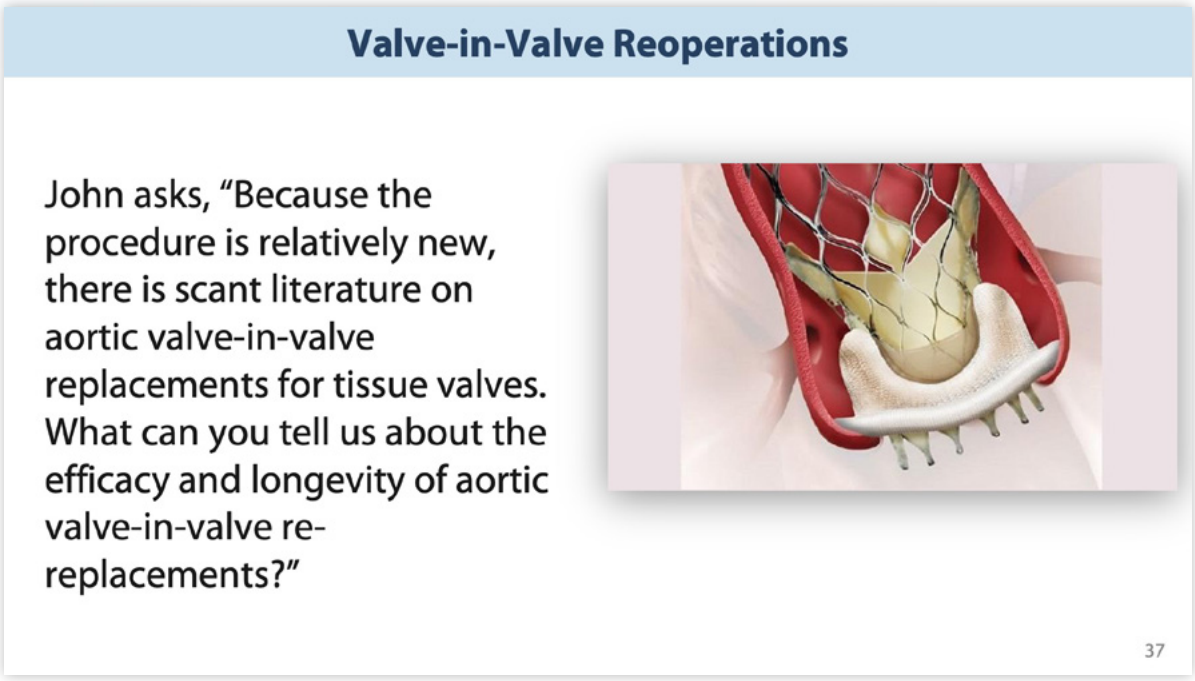
Dr. Hodges: Yeah, that's a great question. This comes up fairly frequently. I think if the mitral valve regurgitation is severe and the valve can be repaired, then that ought to guide the timing of intervention. A good durable mitral valve repair helps this patient for the rest of his life, and if that's the case, then an intervention is reasonable. It's a little bit tricky to know what to do with the bicuspid aortic valve. If the valve looks perfect, that means there's no sub calcification, it opens and closes normally and doesn't leak. It's hard to replace a valve that is perfectly functional. I had this the other day with a young patient. We did a totally normal bicuspid valve, and it's hard to justify replacing that valve.

In a 72-year-old patient, if there's any sign of bicuspid valve dysfunction, that valve is likely to wear out over the course of the patient's lifetime, and replacement with a tissue valve makes a lot of sense because that tissue valve will likely last 15 years or so and is a good platform for a valve-in-valve TAVR procedure through the groin, whereas a bicuspid aortic valve may not ultimately be a very good landing spot or a TAVR valve. Replacing the valve if it's moderately dysfunctional now actually probably sets David up for the best long-term management.



Adam Pick: Let's move on to Mel's question who at YouTube asks, "Will a mitral tear heal on its own? It's moderate to severe regurgitation, and I have shortness of breath."

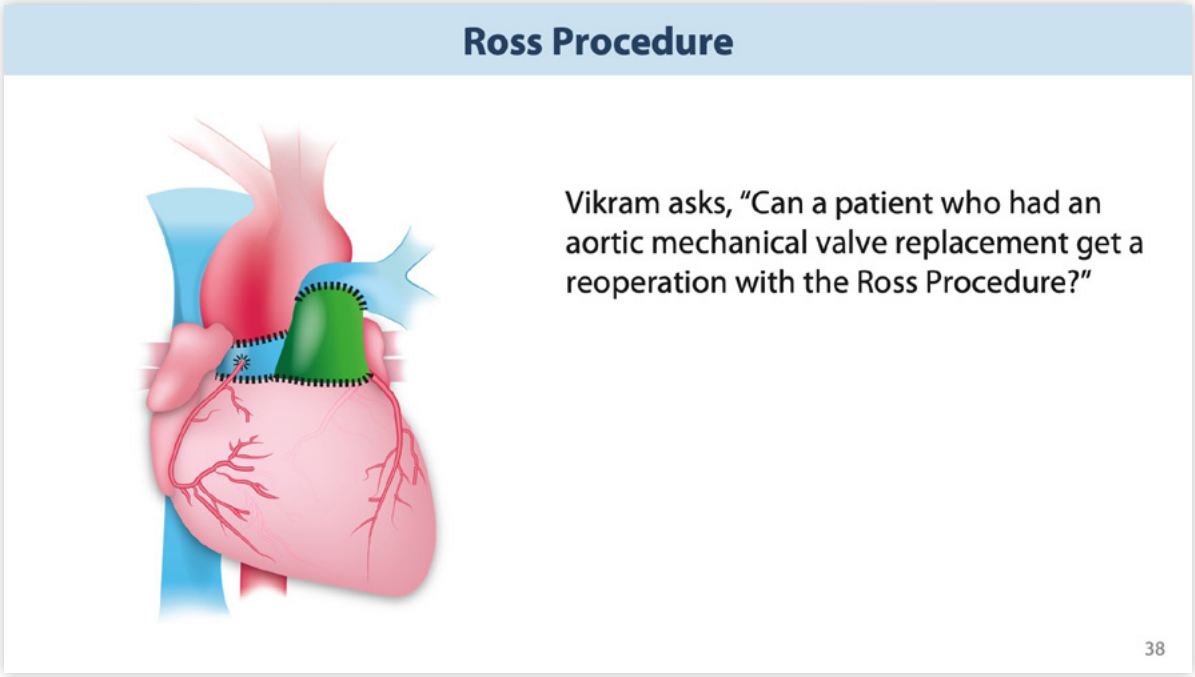
Dr. Medina: Will a mitral tear heal on its own? Tear, I guess to me means is the tear in the valve leaflet itself or is it – sorry, calling it a ruptured cord that's making an appearance of a tear. If they're saying it's moderate to severe and as we alluded to before, you're already having some shortness of breath, it may be affecting you obviously symptomatically, and so it might be prudent to get that further evaluated.



Adam Pick: This question has come up a couple times when we've talked about new technologies as valve-in-valve operations. John asked, "Because the procedure is relatively new, there is scant literature on aortic valve-in-valve replacements for tissue valves. What can you tell us about the efficacy and longevity of valve-in-valve re-replacements?"

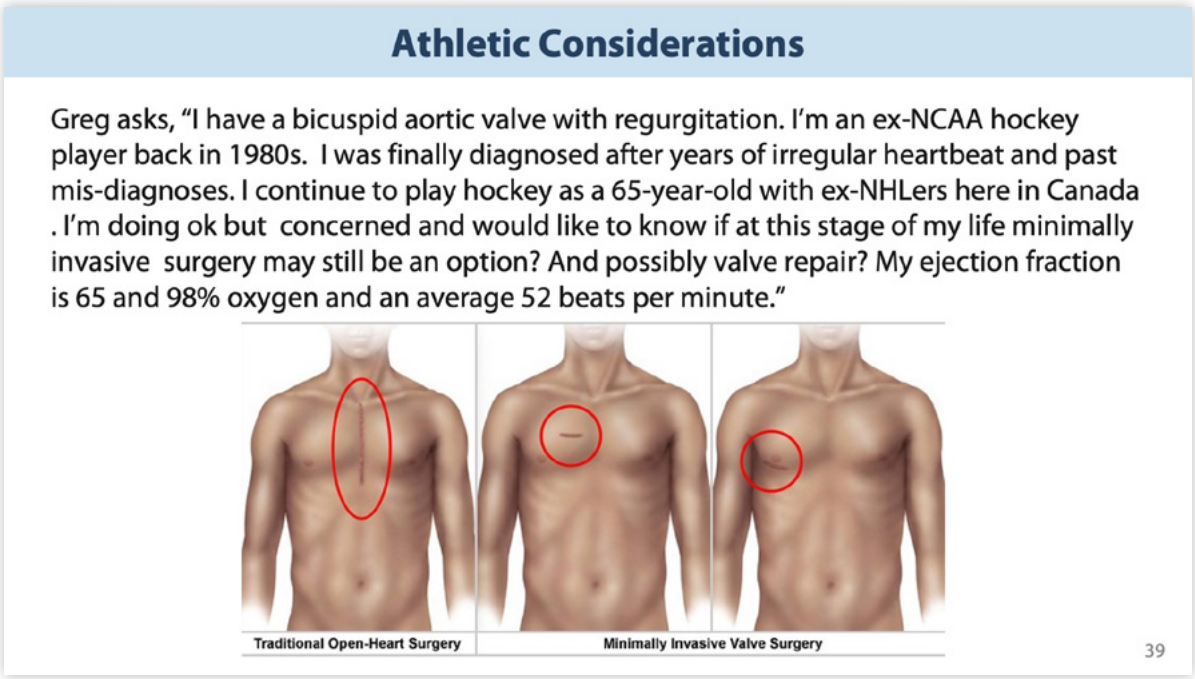
Dr. Johnston: John, you hit the nail on the head. There is scant data. This is a new procedure. What we know about valve-in-valve is, done at an institution that does a lot of these, takes careful measurements of the valve that you have in place and understands what the potential risks are, this can be a very safe procedure. What we don't know is how long it lasts and what some of the longer term issues can be with valve-in-valve. There was a recent study that was presented at one of the major meetings this year comparing a redo surgical valve replacement with valve-in-valve that showed that the outcomes for redo surgery were better.

Those are sometimes tough to interpret because you're comparing all comers and we know that valve-in-valve is very dependent on the type of valve you had to start with, the type of valve-in-valve TAVR, the sizing and how the procedure is done. I would say jury's still out. This is one that really benefits from having an expert heart team, and you should be presented with both options. For a healthy patient, the discussion should be what is going to be best for you, valve-in-valve or redo surgery. In many cases, we may not have great data, but we ought to be able to tell you the relative safety at least of each procedure.



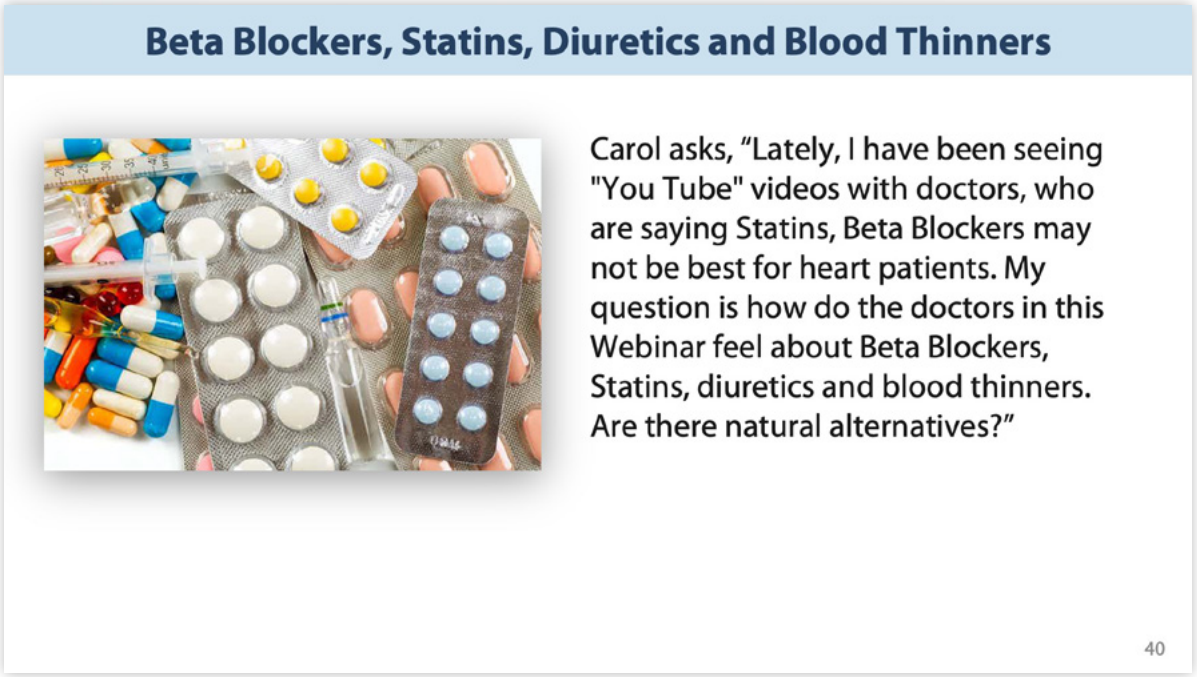
Adam Pick: This one just comes in from YouTube from Vikram who asks about the Ross procedure. He says, "Can a patient who had an aortic mechanical valve replacement get a re-operation if needed with the Ross procedure?"

Dr. Hodges: The short answer to that question is oftentimes yes, and what you need to do is have a team that has excellent imaging, a multidisciplinary team and an expert valve surgeon like Chris Malaisrie who's here at Northwestern, who can look at the anatomy of what was done to the aortic valve the first time, but also the quality of the pulmonic valve, which is ultimately what's used to replace the aortic valve the second time around. Generally speaking, having had a first operation with a valve replacement does not preclude a Ross procedure the second time around. If there's some issue with the mechanical aortic valve and a reoperations on the horizon I think this is a great thing to consider.



Adam Pick: Here's a specific to athletic considerations for people needing surgery. Greg asks, "I have a bicuspid aortic valve with regurgitation. I'm an ex-NCAA hockey player back in the 1980s. I was finally diagnosed after years of irregular heartbeat and passed misdiagnosis. I continue to play hockey as a 65-year-old with ex-NHLers here in Canada. I'm doing okay but concerned and would like to know if at this stage of my life, minimally invasive surgery may still be an option and possibly valve repair. My ejection fraction is 65, 98% oxygen and an average 52 beats per minute."

Dr. Medina: Greg, I think the fact that you're still playing hockey at 65 is quite impressive, and I think you're the picture of health it sounds like. To answer your first question, is minimally invasive surgery still an option, I think so. Both Kevin and Doug do various approaches for minimally invasive valve surgery. Possibly valve repair, I think that would depend on the pathology of your valve as well as what we actually see in the operating room. Your ejection fraction is normal, and so you being an athlete, your heart rate is probably on par with you being an ex-NCAA hockey player. Yeah, I think you'd be a fine candidate for minimally invasive surgery.

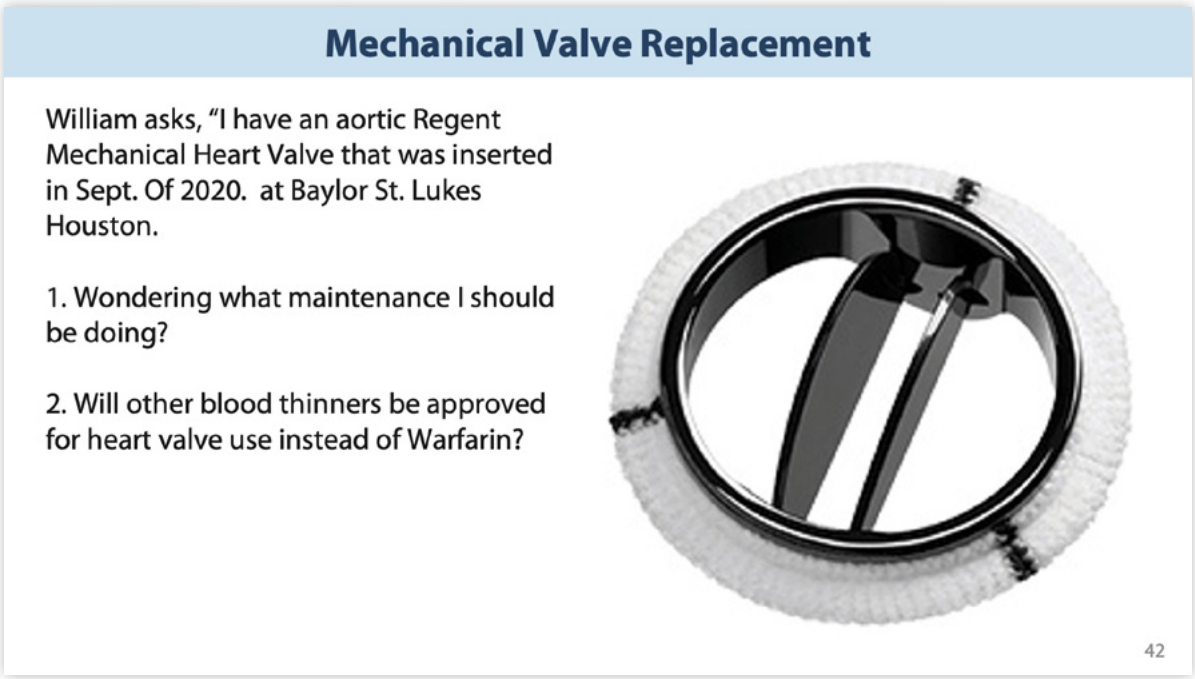


Adam Pick: Great, moving over to Carol who says, lately I've been seeing YouTube videos with doctors who are saying statins, beta blockers may not be best for heart patients. My question is, how do the doctors in this webinar feel about beta blockers, statins, diuretics, and blood thinners? Are there natural alternatives?

Dr. Johnston: That's a great question, Carol. This is one that comes up a lot. People will say I just saw that this new diet will take care of my coronary disease and my valve disease, and I shouldn't have to take any medication again. What I always tell patients is, I would love to see the data. That would be amazing. For some of these problems, like hypercholesterolemia, high cholesterol that

statins treat, there's a great natural alternative, which is low cholesterol diet and exercise, and lots of people can control their cholesterol that way and don't require any drugs. Exercise also helps with hypertension, and so that is one way that people can come off of drugs like beta blockers, but not everyone can control the full extent of their disease with lifestyle modifications or diet or those kind of things.

Dr. Johnston: This is one where you really benefit from having a preventative cardiologist or a preventative medicine doc who really understands the alternatives. What I would say is there's no magic bullet. There's no natural supplement that takes care of all of these issues, and some patients really need these medications. For instance, certain patients with heart failure can only live on diuretics. I mean, they're a lifesaver and a lifestyle saver. If you have a mechanical valve, you absolutely have to be on Coumadin. I mean, that is the difference between life and death. Sometimes I guess is the best response and that will probably evolve over time, but these drugs as much as people like to come off do keep people alive.

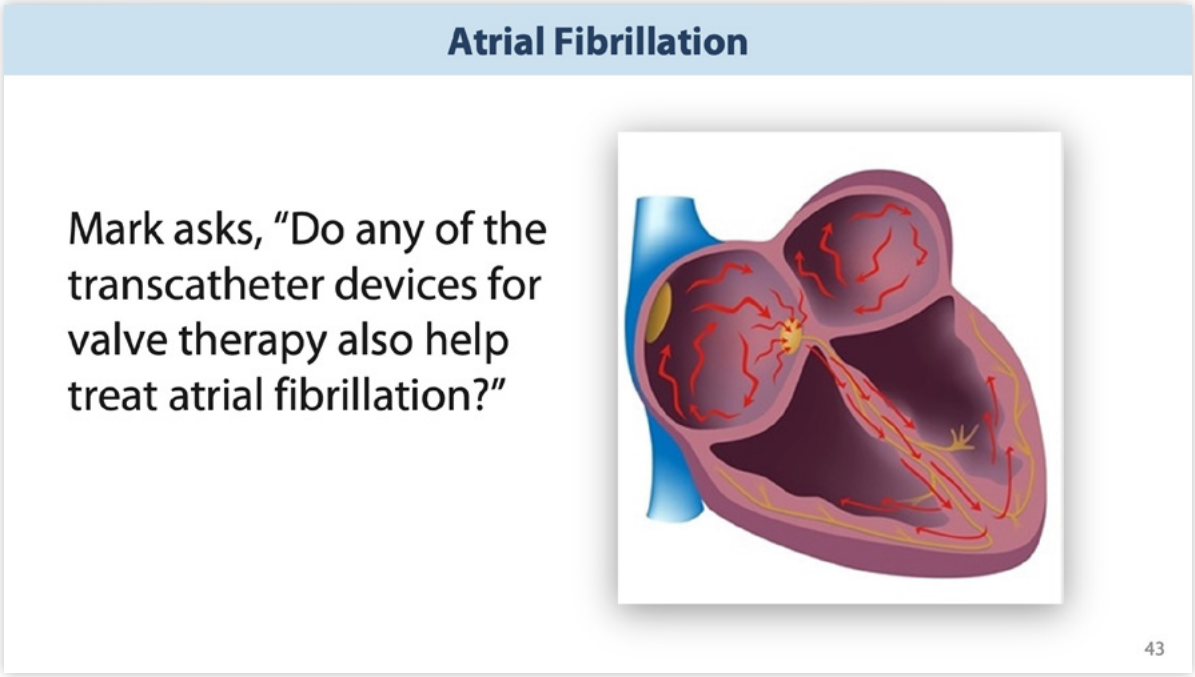


Adam Pick: William asks, "I have an aortic regent mechanical heart valve that was inserted in September of 2020 at Baylor St. Luke's Hospital, wondering what maintenance I should be doing for the valve and will other blood thinners be approved for valve use instead of warfarin/coumadin?"

Dr. Hodges: Yeah, great question, Adam. Hopefully this is a fairly easy one. What maintenance should you be doing besides occasional echocardiograms for surveillance of valve function and cardiac function? None, and that's actually the benefit of mechanical aortic valve. Not everybody is willing or able to take a blood thinner, but for those that are, and especially young patients, these are great prosthesis. The prosthesis that he has is a great one and it lasts for a very long time. The other one, and unfortunately don't have the answer hopefully

he's looking for is that, are there other blood thinners or warfarin at this time? The short answer is no. There have been some studies that have tried other agents and head-to-head comparisons with warfarin, and the results were not good. Studies had to be stopped due to more blood clots, and so right now there's not an alternative.

There's an ongoing study in East Asia looking at this in other populations with mechanical aortic valves, but as of right now, warfarin is the only agent that has been shown to be the safest option for mechanical aortic valves.



Adam Pick: Great, and we're going to talk transcatheter. We're going to go to this question from Mark and then we got one from Sherry who submitted. Mark asks, do you any of the transcatheter devices for valve therapy also treat atrial fibrillation?

Dr. Hodges: I can jump in on this one again, if that's okay, because AFib is a passion of mine, I guess you could say, as nerdy as that sounds. The answer is that they don't treat them in the sense that they don't directly affect people who have AFib. They may help prevent the development of AFib, and people have valve disease but haven't yet developed it. That's maybe one consideration of that. I think AFib is a very important consideration for anybody with valve

disease when picking a procedure. AFib has been shown to be associated with decreased life expectancy, more strokes, more heart failure. It's a really bad actor. While transcatheter therapies often are less invasive and have some very clear short-term benefits, the ability to do what's called a maze procedure and a left atrial appendage occlusion at the time of an open heart procedure is a huge advantage in people who have both valve disease and AFib. I think it's essential that anybody who has AFib brings that up with their surgeon and finds out what is the plan for my AFib; really, really important.

Adam Pick: Thanks for that, Dr. Hodges. Let's stick on transcatheter. This is from Sherry who submitted, "I'm curious to know if doctors are recommending transcatheter valve replacement for patients under 60 years of age."

Dr. Johnston: That's a great one. The answer is it depends on what else is going on with the patient. The data on low risk patients with transcatheter aortic valves in particular, so that's where that we have the most data, is a little confusing. It's often used to say, oh yeah, well you're 55 years old, you can get a TAVR valve and have a great result, but the average age in the low risk studies was in the mid 70s. We don't have a lot of data on young patients having transcatheter valves. In particular, one of the considerations is that patients around age 60 tend to have bicuspid aortic valves, and there's some data to suggest that TAVR doesn't work as well in bicuspids. The outcomes are not as good as they are in tri leaflet valves. Again, this is one of those areas where it's hard to generalize from transcatheter valve studies done 10 years ago in 80-year-olds to a 60-year-old. It's a very different longevity that we're looking at, very different outcome.

At Northwestern in general, for younger patients, most younger patients with valve disease, we would consider surgery first. The data is more robust for that. That being said, there are people who have reasons why there are higher risk for surgery or where we expect that other things are going to go wrong with the heart. A perfect example is radiation heart disease, where if you need a valve

replacement of your aortic valve now, chances are your mitral valve is going to be involved in the next five years. That's a case where we do recommend TAVR for younger patients, and it doesn't burn any bridges for us for the longer term.

Adam Pick: Great, thanks, Dr. Johnston. We are coming to the end of the hour, but please don't jump off the line. We've got 49 questions. I know Dr. Johnston, Dr. Hodges, Dr. Medina in the past, you guys have gone ahead and answered these questions after the webinar. Would that be something that would be possible and then we can post all the answers that you provide? Is that something the Northwestern team can do?

Dr. Johnston: Of course.

Adam Pick: All right, fantastic. On that note, before you hang up, I'd like to go ahead and as we celebrate heart valve day and heart month, I want to thank the expert panel today, Dr. Johnston, Dr. Hodges and Dr. Medina for being with us. This was a very quick hour. Thanks for all the tips that you shared with the patients in our community. On that note, I'd like to thank the patients in our community, the families and friends that come together here at heartvalvesurgery.com to really help each other get the best possible outcomes for their valvular therapies. Lastly, what I'd like to do is thank you for the survey as we wind down the webinar. This will be coming up on your screen as soon as we say goodbye. Once again, Dr. Johnston, Dr. Hodges, and Dr. Medina, thanks for being with us today. Thanks to our community. As we always say here, keep on ticking. Thanks so much everybody. Have a great rest of your evening.

Dr. Medina: Thanks, Adam.

Patient Resources

Since 2006, HeartValveSurgery.com has developed several resources to help you better understand your diagnosis, your treatment options and your recovery.

Listed below, please find resources created exclusively for patients and caregivers. We hope they educate and empower you.

- Adam's Free Patient eBooks - Download 10+ free eBooks about heart valve disease and treatment options for aortic, mitral, pulmonary and tricuspid valves.
- Heart Valve Learning Center - Visit the Heart Valve Learning Center to access over 1,000 pages of educational information about valvular disorders.
- Patient Community - Meet people just like you in our patient community. There's nothing better than connecting and learning from patients who are sharing their stories in our community.
- Surgeon Finder - Find and research patient-recommended heart surgeons that specialize in heart valve repair and heart valve replacement procedures.
- Heart Hospitals - Learn about medical centers that have dedicated teams and resources that specialize in heart valve therapy.
- Adam's Heart Valve Blog - Get the latest medical news and patient updates from our award-winning blog.
- Educational Videos - Watch over 100 educational videos filmed by the Heart-ValveSurgery.com film crew about heart valve surgery.