

BATIENT TIPS FOR HEART VALVE DISEASE



Authors



Dr. Mustafa Ahmed

Interventional Cardiologist UAB Medicine (205) 975-1888 <u>Learn More.</u>



Dr. Gregory Fontana

Cardiac Surgeon Cardiovascular Institute of Los Robles Health System (805) 852-9100 <u>Learn More.</u>



Dr. Heather Johnson

Preventive Cardiologist Baptist Health South Florida (561) 955-2131 Learn More.



Natalie Kelley, RN

Valve Program Coordinator CHRISTUS Trinity Mother Frances Heath System (903) 606-2049 Learn More.



Adam Pick Patient, Author & Website Founder HeartValveSurgery.com (888) 725-4311 Learn More.



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

Table of Contents

Featured Speakers	2
Introduction	4
Why Have A "Valve Disease Day"?	8
Tip #1: The Diagnosis Can Be Confusing	. 12
Tip #2: Listen To Your Body	. 19
Tip #3: Get Educated and Get Involved	. 26
Tip #4: Keep Routine Follow-Up	. 32
Tip #5: Be Open-Minded About Treatment Options	. 35
Tip #6: Think About A Lifetime Management Plan	. 46
Tip #7: Get A Second (Or Third) Opinion	. 51
Tip #8: No Substitute For A Healthy Lifestyle	. 57
Questions & Answers	. 59
Heart Valve Calcification	. 60
Cardiac Depression	. 61
Aortic Aneurysms & TAVR	. 62
Atrial Fibrillation	. 63
Tricuspid Valve Diagnosis	. 64
TAVR Risk Management	. 65
The Future	. 67
LifeIsGoldenWithEvolutTAVR.com Campaign	. 69
HeartValveSurgery.com Patient Giveaway	. 71

Introduction



Adam Pick: Hi, everybody. My name is Adam Pick. I'd like to welcome you to the webinar titled, "The 8 Must-Know Tips for Heart Valve Patients", on this very special day, which is the National Heart Valve Disease Awareness Day. If I have yet to meet you, I am the patient who started <u>HeartValveSurgery.com</u> 17 years ago in 2006. The mission of our website is very simple. We want to educate and empower patients just like you. This webinar, which has had over 1,500 registrations from patients in countries all over the world, was designed to support that very important mission.

Throughout the webinar, you're going to be in what's known as "listen-only" mode, but I encourage you to submit your questions in the control panel that's on your screen. I'll explain why as we look at the agenda.

4



For today's session, we're going to have some introductions. Then, we're going to ask and answer the question "Why have a Valve Disease Day?". Our experts are going to share eight tips with you. We're going to get into an interactive Q&A session. Then, we're going to lead into a set of closing remarks in which we'll talk about the our patient giveaway. Then I'm going to ask you to complete a very quick, five-question survey.



I'd like to share that our sponsor for today is Medtronic. Medtronic is one of the world's largest medical device companies. Specific to valvular disease, they released their first heart valve in 1977 and have been innovating every since then. As you may know, they specialize in <u>minimally-invasive transcatheter aortic</u> <u>valve replacement (TAVR)</u>, which has been implanted in over 500,000 patients.

When it comes to Valve Disease Day, I can tell you that Medtronic is all for it. Not only have they made these great cookies, which I got to taste when I was at their headquarters in Minneapolis. But, they really are focused on driving awareness and helping people understand that it's so important to learn about the lifetime management of heart valve disease. We're going to talk all about that today. Thank you, Medtronic.

Our Expert Panel







Dr. Mustafa Ahmed Interventional Cardiologist







Dr. Gregory Fontana Cardiac Surgeon

Now, when it comes to our expert panel, I'm going to share with you that growing up, I read a good amount of comic books. I would submit to you that we have a "Fantastic Four" with us today. We have Dr. Heather Johnson who is a preventive cardiologist. Dr. Johson, thanks for being with us today.

Dr. Heather Johnson: Thank you so much for having me. I appreciate it, Adam.

Adam Pick: Yeah, we have Dr. Mustafa Amed who's an interventional cardiologist. Hi, Dr. Ahmed.

Dr. Mustafa Ahmed: Hi, I'm looking forward to this. Thank you.

Adam Pick: We have Natalie Kelley who is a valve program coordinator. Thanks for being with us, Natalie.

Natalie Kelley, RN: Thank you so much. Hi, everyone.

Adam Pick: We have Dr. Gregory Fontana who is a cardiac surgeon. Dr. Fontana, thanks for being here.

Dr. Gregory Fontana: Good afternoon, everyone. It's my pleasure.

Why Have A "Valve Disease Day"?



Adam Pick: Let's get started with a very big question, which is, "Why have a 'Valve Disease Day'?" I'd like to start with the commonality of valve disease because about 2.5% of the US population has valve disease. I don't know about you, but on my street alone, my neighbor to the left had an aortic valve aneurysm procedure and my other neighbor kitty-corner had a mitral valve repair and coronary artery bypass graft. This disease is all over the place. Over 10 million people in the United States. The big point I want to make there is you're not alone.

The other thing I want to share is that the disease typically skews up in age, so 13% of people who have the disease are age 75 or older. As you know, I'm a patient. I had the disease go to a severe level when I was 33 years old. I needed surgery much younger than normal. Sad fact, 75% of Americans know little to nothing about heart valve disease. That gets even worse when you realize, when it comes to treatment, this is a very under-treated disease with less than 40% of people getting treatment for severe aortic stenosis.



When you wrap all that up, the moniker for heart valve disease is the "silent killer". According to estimates, about 25,000 will lose their lives due to this disease.

Why have a "Valve Disease Day"? I think it's very apparent. We need to drive awareness to this health burden.

So, what has happened to address this issue? We started Heart Valve Disease Awareness Day back in 2017. We've got over 100 organizations that participate it. It's recognized by the US Department of Health and Human Services. When it comes to statistics, we're doing some good. We've had over a billion impressions and reached nearly 166 million people.

We know why we're here. We know what we're doing.

The Four Heart Valves



Adam Pick: To level-set everything before we talk to the experts, I just want to make sure everybody is aware there are four valves in your heart. The aortic valve, the pulmonary valve, the mitral valve, and the tricuspid valve. If they don't work properly, that can lead to a lot of debilitating symptoms and some very sad situations for friends and family.

Heart Teams Can Help You!



Adam Pick: You're not alone in the situation. "Heart teams" are designed to help you. Today, we have several great members of a heart team. As you can see here, it's not just one doctor that should be helping you.

You really want to find the time to associate and establish with a true heart team that's specializes in heart valve disease, whether it's the general cardiologist, a preventive cardiologist, an interventional cardiologist, the valve clinic coordinator, and cardiac surgeons, just to name a few.

Tip #1 – The Diagnosis Can Be Confusing



Adam Pick: To get started, we're going to turn it over to Dr. Heather Johnson who, as I mentioned, is a preventive cardiologist. She is at the Christine E. Lynn Women's Health and Wellness Institute. She's an associate professor at Florida Atlantic University. She is based out of the Boca Raton Regional Hospital and is part of the Baptist Health South Florida. Dr. Johnson, thanks for being with us and please proceed.

Tip #1: A Heart Valve Disease Diagnosis Can Be Confusing

Dr. Heather Johnson: I appreciate the invitation to participate. Really briefly, I know before we started officially, we were chatting and Adam was asking about preventive cardiology. I'm also in that special figure you just saw as far as "general cardiologist". That's my big hat and so many things I do within that. We'll talk about prevention.

As your general cardiologist in relationship to valve disease, you saw the figure about having imaging as far as connecting you to special valve clinics. I work very closely with the primary team helping you and your primary team understand your diagnosis about valve disease, walk through that journey, and then if needed, move you on to the next step as what should be done about it.

I have two key tips that I will highlight. The first one is that heart valve disease diagnosis, any of them can be confusing. I do recognize that. It's one of those things in which I want to highlight as why it's important that as, you walk through this journey, you have various people to help you understand it and have the best quality and healthy life moving forward.



We're going to review two key types of what we call heart valve disease or heart valve conditions. Adam has already highlighted the four types of valves that we have. However, when we talk about what types of disease, again, there are variations to this, but there are two key types. Number 1 has to do with the term stenosis. One of the most common is aortic valve stenosis. We see the leaflets in the picture here and they look kind of thickened. They become stiff. What happens is that literally is a narrowing of your valve. As the size or the orifices or that opening gets smaller, imagine your heart trying to push that blood through the valve. Naturally, if it's a smaller opening, the heart is working harder. That is what we call stenosis or narrowing.

Now, we're going to talk about the second big type. That's the term regurgitation. You may have heard people say, "I have a leaky valve". That's a term you may hear. No blood is not leaking out of the heart. I wanted to clarify that because I've had some people ask me that, but the term regurgitation has to do with the leaflets of the valve, the heart squeezes and the leaflets come together, there's a space between those leaflets. Instead of all the blood moving forward, some of the blood comes backwards through the heart. Imagine the heart having to work overtime because it's trying to push the blood forward, but because of the separation, it leaks backwards.

When it pushes the blood forward again, it has a little bit more work to do getting all the rest of that blood forward here. It's called a leaky valve. The blood goes backwards through heart. It doesn't all go backwards. There's different amounts that goes backwards. It does eventually go forward, but the key thing is that the heart is working harder. It's doing extra work. You see in the picture. You see those yellow arrows as far as the smaller ones in that top chamber. That's one of the things. Imagine, eventually over time, sometimes parts of the heart get larger because it's trying to accommodate some of that blood going backwards a little bit more blood.

For both of these conditions, your team may mention that they hear a "heart murmur". Sometimes, your primary care physician or primary care clinician could be one of the first people that say, "I hear a heart murmur". I want to take the time and highlight that when we first learn about a murmur, it doesn't mean that we have a dangerous condition at that moment. Heart murmurs are a sound. It's a sound that we hear. It can be from other things, not just from the valve. I try to make a point to explain to a patient if I hear a murmur, explain that it is a sound that I'm hearing and I will tell the patient if I believe it's coming from the valve.



When we talk about the valve itself, I want people to understand that when we first assess the valve, we're trying to help you understand is the condition mild, moderate, or severe. Because we may see the regurgitation, see the stenosis, hear certain things on exam, it doesn't mean that you have a severe disease.

It could be that some valves can have certain natural regurgitation or leakage. It's there. There are different terms we may use in the medical field. Many people for decades can have mild/trivial traits, other forms when we talk about, for example, regurgitation or leakage, but we need to know that when we talk about disease of the valve, stenosis, narrowing, regurgitation where we're seeing changes of the valve, changes in that how much is going backwards, that's what we mean by a progressive disease. Now, we're going to talk about the importance of listening to your body, but because these valves may have narrowing or regurgitation does not necessarily mean you're going to have symptoms. That's why we talk about the importance of having your heart checked. The other thing we chatted about a little bit before this started is that sometimes there are other heart conditions related to having heart valve disease. For example, for the aortic valve, one of the main valves and it's connected to the actual aorta, which is the main artery coming out of the heart. There can be enlargements or dilation. You may know the term aneurysm in relationship to it. We also know that the heart has electrical system running through it, these fine fibers. There can be electrical situations such as atrial fibrillation or different heart rhythms that can take place, either by itself or in relationship to valve conditions.

We also know that heart disease and valve disease can sometimes go together. Adam, just shared that in his neighborhood someone having a valve procedure and also having to have what we call bypass surgery in relationship to valve disease. It's one of those things in which when we see valve changes, we also look for other possible heart conditions.

The good news about all of this is that although true heart valve disease does represent structural changes, changes in the way the valve is functioning, changes in the challenges of the flow through the heart, it is definitely something that can be monitored and treated to definitely try and maintain quality of life.

<section-header><section-header><section-header><section-header><section-header><section-header><text>

Dr. Heather Johnson: Big Tip Number 2 is, "Listen To Your Body. Many times, be it in general cardiology or even preventive cardiology, people want to know what's going on with their heart.



- There are many different symptoms
 - Chest pain
 - Discomfort
 - Palpitations
 - Dizziness
 - Passing out
 - Fatigue
 - Ankle swelling
- Is it your valve or something else?
 Artery disease, Afib, heart failure
- Additional tests may be needed

Amarikaan Hacart Association			9476	1.1
eart Valve Dis	ease	Sympto	m Tro	acker
Pain, tightness or pressure in the chest	🗆 Never	C Occalendly	O Often	D Always
Lightheadedness or distiness		D Occasionally	D Offen	C Always
Shortness of breath	Dieer	C Occasionally	C Ofen	C Always
Repid futtering heartbest	D Never	Dominally	D Often	C Always
Pointing	D Never	Dominally	D Ofen	D Always
Difficulty sleeping or sitting up	D Never	Dominally	D Often	D Alongs
Swallen ankles or feet	C Never	D Occasionally	C) Often	D Always
Difficulty wolking short	D New	D Occaionally	D Often	D Always
Not engaging in activities you once did	D Never	D Occasionally	C) Often	D Always
t of the above symptoms happen r	nort frequer	ntyr i	R's Importo	ent to recheck
hactivities cause you to feel winde		Ibresili?	they are per- cone profes	tting better or to your health sional about sumptoms to
			Gettermine	freedmand.

I say that we, as individuals, all present very differently. When we focus on heart valve disease, sometimes when the symptoms began, we may not know what's going on or even if it's the valve.

This slide provides an overview of some symptoms. We talk about chest pain, but I actually like to use the term chest discomfort. Some people talk about flutters or skipping in their heart beating. Broadly, we call those palpitations. Dizziness or lightheadedness, passing out, or people may say close to passing out, just feeling fatigued, winded. Ankle swelling, an individual presented to me solely with ankle swelling, in fact, his wife noticed it, and sure enough, he had valve disease. It's not to say that if you have these symptoms, you have a significant valve disease. We think broadly, but if you see on the other side of the slide here, the American Heart Association has what is called the <u>"Heart Valve Disease Symptom Tracker"</u>. It allows you to be able to check off or remind yourself what you might have been noticing. It's available at the American Heart Association website. Again, they talk about the shortness of breath, difficulty sleeping, having to sit up while sleeping, things we may not even realize we should discuss when we're having our heart checked or just talk with our doctors about.

The other thing is that we may notice people may slow down a little bit. You're not doing the same activities. When we ask about, well, are you having any symptoms, you say no, I often times will ask, "What are you doing?" If you tell me you've slowed down, we dig a little deeper as to why.

This allows us to be able to see and be able to evaluate... Is it your valve. Is it something other than your valve? We need to look for arteries, look for rhythm issues, think about heart failure, all of those factors.

The key thing about this is... In addition to history and discussion and us talking back-and-forth about how you're doing and we compare how you're doing to how you were previously doing, we then determine what's the next best step as far as various tests that may be needed for your specific presentation.

Different Tests Available to You



I want to highlight there are many different tests that are available. It's not one size fits all. It's not that every person will see all of the same tests that we have available. Some of the more common things that we tend to start with is an ultrasound of the heart. You may also know the term echocardiogram or "echo" for short.

In that figure, we see the gentleman laying down and call that a probe of the chest and taking pictures. We're able to see all the different heart valves, how they're functioning, how the heart is squeezing, also look and see as far as signs of heart failure or damage to the heart. It's one of those the basic test we may use.

Now, there's different types of ultrasounds that we have -- two dimensional, we have the kind where you look over the chest, and sometimes people are even sedated for what's called a transesophageal echocardiogram (TEE) where the

probe goes doing the throat and we're able to look much closer at the valve. Don't worry. You're sedated. You're sleeping.

The other more common test right away we tend to do is an electrocardiogram, for short either EKG or ECG. That's the pink figure you see where we're checking the rhythm. What's going on? How's the heart rate? Is it too fast? Is it too slow? Is the rhythm changing at times? Sometimes you're asked to even wear a monitor for a bit of time for us to be able to see what's going on. I always clarify because sometimes there's confusion of echo versus EKG. When I'm asking what you had done, I always ask did you have the "jelly on the chest", that's the echo, the ultrasound. We sometimes do CAT scans, MRIs, various tests that are available. Just remember, the team's goal is to determine what's best for you.



The last point that I want to highlight is that when we talk about heart valve disease, that there can be decades or years, and the timeline definitely varies, as far as progression of the valve over time. Many people, when they first learn about valve disease, something that we have to monitor, and we'll talk about how often to monitor based up what condition we see, what degree it is - mild, moderate, or severe - there can be quite a bit of time as far as before you have any symptoms. We want to highlight that especially when those symptoms develop in relationship to valve disease, that is an important moment.

Understandably, people are not as excited when we mention the need of needing to have some valve procedure. But we're doing it because of the fact that we know that, especially when those symptoms develop, it is super critical to actually try to help save your life and preserve your quality-of-life as much as possible. There may be second symptoms as far as shortness of breath, passing out, heart failure symptoms. Unfortunately, we know that there's limited time as far as really much more serious events after that. I always say make sure you have timely follow-ups. If there's mild findings, your doctor may say we may not need another ultrasound until at least a year or later. Sometimes they want it yearly, less than yearly, different types of imaging, so stay in touch with your team. We try and move sooner and not just wait for symptoms. The valve as far as what we do has definitely changed overtime, but understanding listening to your body and allowing the team to get you to the right place in a timely manner is critical to preserve the quality-of-life and help to provide all possible options to you.

Tip #3: Get Educated and Get Involved



Adam Pick: Great, thanks, Dr. Johnson. Now we're going to hear from Natalie Kelly, who is a valve program coordinator at CHRISTUS Trinity Mother Frances Health System. She is also an intensive care nurse. Thanks for being with us, Natalie.

Tip #3: Get Educated and Get Involved

Natalie Kelley, RN: My name is Natalie Kelley and I'm a registered nurse and a valve program coordinator. A little bit of background about my role in the heart team is that I get to provide comprehensive seamless care from that initial referral all the way through long-term follow-up for valve patients. I often get the opportunity to go between surgeons, cardiologists, patients, and many other disciplines. I think that the most gratifying aspect of my role is just that program ownership and being able to serve our patients through that personal communication with our heart team, the patients themselves, and also their families.



My first tip for you is to "Get educated and get involved". It's certainly normal to have fear and even some apprehension prior to a meeting with your heart team, but I think that understanding the steps of your diagnosis and what options that you have for treatment is so important. It's also important to be an active participant in your care. It starts with doing some homework. Research your care provider team. Learn what options are available to you. Don't assume that all heart teams are the same. This might include techniques, number of procedures, skillsets, and capabilities. I'll also encourage you not to dive too deeply into the internet. Start with some reputable sources for your information. Certainly being on <u>HeartValveSurgery.com</u> is a great place to start. You can also consider looking at <u>CardioSmart</u> and <u>Heart Hub</u>.



As you're doing your homework, doing your research, getting prepared to meet the heart team, I would encourage you to make a list of questions that you want to ask your heart team. Write them down and bring them with you. Bring a support person to the appointment with you. This is someone who's going to be there for you who's going to listen and who's going to support you. Think about communication during the appointment. I want to encourage you to be engaged. Clearly communicate with your provider team. Again, writing those questions down is so important. Make notes of the points that you want to cover to ensure that those important questions and information, your questions get answered by the team. Also, just know that this is a two-way discussion. Don't be afraid to ask tough questions. Don't write off your symptoms as a sign of aging. Be engaged in the discussion. Also, remember that before making an decisions, it can take time to process information and ultimately you are in the driver seat and it's okay to take time to wave those options before you make any final decision. In doing so, I would also encourage you to set goals with your heart team. Think about those personal goals.

Define where you want to be after the procedure and what you might hope to gain through going through the whole process and operation. Is it enhancing your quality of life, keeping up with your children, keeping up with your grandchildren, continuing to work and do your hobbies? It may look different for everyone. That's where the personal touch of the heart team comes into play, but managing your expectations going into surgery can really allow you to have that successful recovery.

Tip #3: Get Educated & Get Involved

Am I a candidate for a less invasive procedure? How will treatment of my heart valve disease impact my life?

I want to take a deeper dive into questions from my favorite educational tool for heart patients. It's called <u>My Interactive AS Journey</u>. This resource is directed towards patients with aortic valve stenosis, but the questions that I'm going to cover and list come from this tool. They really do apply in any topic scenario with the heart team.

21

Let's talk through some of these questions. Why is treatment necessary? How effective are my treatment options? How do I know the best treatment for me? What are the risks associated with the treatment options? Am I a candidate for a less invasive procedure? Will the treatment of my valve disease impact my life? How is treatment going to impact my life? Really, from a patient perspective, being well prepared and having these questions ensure a more effective and informative discussion with the heart team.



Natalie Kelley, RN: That brings me to my next tip. We spent a little time on before you meet with the heart team. What about after? When the procedure is already concluded and you're ready to get back to your life, what's another tip for you? That is "Keep Routine Follow-Up" with your cardiologist after your valve procedure.

32



After your surgery, regardless of the procedure, you are going to leave the hospital and have those scheduled follow-up appointments. A lot of the time, if you have open heart surgery, you may have a one or two week post operative visit followed by a six-to-eight-week follow-up with the surgeon. Then for TAVR and those less invasive procedures, you also have a one-week phone call or visit followed by a 30-day follow-up with an echo, and then a subsequent one-year follow-up with an echo.

A lot of times, those short-term annual appointments, you're going to walk out of the hospital with this planned for you. What happens after that now that you're through surgery, things are clear to resume normal activities, you're back to your normal lives? I would encourage you, no matter what type of valve procedure that you had to address your valve, to see a cardiologist on an annual basis. What is that going to do for you? It's going to allow you to continue to meet with an expert. Your cardiologist will be able to conduct a physical exam, listen to your heart, and also address any issues or concerns that you may have. It gives the cardiologist and you, the patient, the opportunity to recognize and address any issues promptly.

Eventually, your cardiologist may recommend an echocardiogram to test the strength of your heart and the function of your valve and really it's those annual visits that allow your doctor to look after those trends and monitor your heart valve. It really is an essential and ongoing part of care for heart surgery. It's definitely going to extend those benefits of surgery.

We talked a little bit about defining those goals and expectations. These are the goals and expectations served out through the annual follow-up. My last point would be that keeping that follow-up is going to enhance your quality of life.

Tip #5: Be Open-Minded About Treatment Options



Adam Pick: Moving on to Dr. Ahmed. He is an interventional cardiologist at UAB Medicine. He's also an associate professor. He's been featured in over 90 medical publications. His specialty is transcatheter valve therapy at UAB Medicine in Alabama.

Tip #5: Be Open-Minded About Treatment Options

Dr. Mustafa Ahmed: I'm something called a structural heart specialist and it involves an interventional cardiologist. What that really means is if you go 20 years ago, just 15 years ago, when I went into the field, it was one option. You have valve disease. There's very few valve specialists back then. You go to an operation maybe about 15 years ago. Over time, what's happened is so many – there are so many options now, many done by traditional surgery, many done by minimally invasive, and many done by this thing called transcatheter, which means how do we maybe go through a vein or go through an artery in a manner that can maybe treat those people when we started this field that felt too high risk to have any type of surgery.
Now, through a very kind of wonderful processes of technology and teams such as that assembled here today talking to you and everyone involved, we now have a whole array of options and really work closely with this thing called a "Heart Team" and the interventional cardiologist and the structural heart specialist really mainly how do you go through a catheter and do that and evaluate this disease.

The most important thing to get across, when you have valve disease and you're told, okay, your aortic valve is tight or your mitral valve is leaky. No normal person wants to hear "go and get your chest open and have an operation" because they've read about maybe some option where, hey, one of my friends or my parent, they went through the leg and they fixed that valve and they went home the next day and they did great.

The reason this is such a critical tip is whenever you're going to get evaluated for valve disease, the key is to understand all the options, really look across everything and see what the best option for each individual case is and be open minded. What does that mean? I'm going to give you a couple of examples.

<section-header><section-header><section-header><caption><image><image>

Two things here, on the left is an aortic valve replacement. We'll show you a little video of that in a while where a procedure through the leg called the TAVR procedure or TAVR in Europe, you've gone through the leg and you within 20 minutes put this heart valve in, expanded it into place, you are lightly asleep and before you know it the procedure is finished if all goes well. Later in the day, you get up and you're walking around and you have a discharge the next day. You follow up and that's the whole experience. That's a way of replacing a valve.

On the right, you have a band and a repair of what's a mitral valve surgery, which is for a leaky mitral valve, this repair, but that involves a surgical approach, and that might be, we'll talk in a minute, but that might be with a robot surgeon or it might be through an open heart surgery or it might go through the leg and there's options called a mitral clip. Each treatment has very different advantages and disadvantages. A TAVR procedure might be great if you are looking at a way that lasts a long time. We'll talk about this in a minute, too, lifetime management. If you have at the same time disease of your arteries and you have at the same time disease of the aorta and those things are there but they're not critical yet but they're getting on towards that, it is actually much more complicated to go and put a valve in like this and then do some stents in the arteries or maybe go ahead and watch that aorta over time. If you said to someone, hey, we're going to replace that valve, it can be done quickly and you go home and that's all there is, that's fine, but in many circumstances, it is better to do an open-heart operation or some stents or some bypasses instead of stents and replace that valve and set up another procedure down the road nicely and also repair the aorta.

What you don't want to do is go for treatment, which sounds absolutely brilliant compared to the other one for instantaneous purposes, but then in 1, 2, 3, 4, 5, 10, 20 years undergo a plethora of treatments which become more and more complex and actually limit the treatment options available after that. Same with the mitral valve, you can go through the leg and maybe put a clip on the valve and do a repair. At the same time, if you are high-risk and you are not the best surgical candidate, great, we have data on that going a few years and it can be done, but then we have mitral valve repair. Yes, the recovery is a little bit longer, but then we have people and data and studies looking at people over 30 years.

You have to ask yourself, when you go and speak to a physician or you go and speak to a provider and you're like, hey, what are my options, never go in – my biggest point in this tip is never go in and say, "Hey, I want the most minimally invasive thing possible." That absolutely should be on your mind. It would be on my mind as well if I was going in and getting this done. Really, what you're asking is what is the best treatment for me in the totally of the conditions I have that not just takes into account my experience when going in but really builds a management plan that takes into account all of the other things I may have.

If you have an aortic valve and you're having a replacement and your aorta is large, that needs to be discussed beforehand. Or, if you have a lot of arteries that people put in a stent, that needs to be discussed, and if you seem like you're having a mitral valve treatment and someone is offering you mitral clip, is the surgeon that you saw at the same time experienced and do they understand that? Really, all of this is discussed by a good functioning heart team. The best way to approach this tip of the open minded is to say, okay, I'm going to go to a team that has all of these options available. Everyone in these teams is actually pretty good at these options. They've discussed not just the most minimally invasive option but the other options, too, and then take all that together and come up with a decision that leaves you in an advantageous point both instantaneously and in the future.

Listen, I've had people come to me and they're 60 years old and they're demanding about through the leg and their reason – they understand. They understand you may have to go in and it may last long but it may not last as long and going back in 20, 30 years may be different and they understand they may need to have a surgery down the line. However, after all that, they are making that decision. Someone might say to me, listen, I'm flying right now and I'm in these few years and I can't have surgery now and this is why. I one million percent understand. That's all we want for everyone. We want absolute understanding, shared decision making, not just go in someone can do through my leg, I want to get it done, great, you go home, because then you've got all these problems afterwards.



Let's rush through a couple of slides here. Here's some different approaches that are surgical.



Let's show this valve because I do want you to see these options that can be done of a valve. This is what we do now most commonly to replace an aortic valve. You'll see there's the heart and it's beating and it's an aortic valve which we're going to zoom in on now. There it is. It's opening and closing. You can see that in the big aorta coming in.

Now we're looking on top of that aorta. See, there's calcium build up on the valve, the most common cause of why that valve becomes tight. In these procedures while we now do this TAVR procedure, we are going to come back and that red right there which has now become highlighted, there's the arteries. We can now go through those arteries with something that is as big as a pen in terms of profile. We go through the leg and up through the heart. We mainly through the leg here can put a valve through here. We will throw that through the body.

I really wish it was as easy as this video is making it look. I mean, it is quite straightforward, but definitely we don't just – it doesn't just go like this, but there you go. The valve's now come through and you can see it being expanded into place. We have a chance with the <u>Medtronic valve</u> here to recapture and reposition this and really put it in perfect place. There you see a new valve and it will be released. The actual valve deployment itself once you're in there may take another minute longer than this. We take out the system and the wire and you have a new valve. That's called a transcatheter valve.



The TAVR procedure which we just showed you, when we first started that for patients, it's super high risk. We used to say, okay, this may last five years, this may last a few years, and we used it on people who really couldn't have an operation. Some of the data coming out, and here's the Medtronic data from the Evolut valve, is showing not just that one year, two years, three years, four years, not only is it really matching outcomes seen from a traditional surgical approach sometimes, assuming this is the best option, but we actually have data going out five, six, seven towards ten years.



We're telling patients this is lasting probably as long as a surgical valve you would've had before and there's further options beyond that.

Tip #6: Think About A Lifetime Management Plan

Tip #6: Think About A Lifetime Management Plan

Dr. Mustafa Ahmed: Okay, so let's move on here. The final thing I want to leave you with is the lifetime management plan. Whenever you do a procedure, and this is your main to the whole decision-making process in the first point, if you do go in, and I want you to use the example that you're 50 years old. If you're 80, 90 years old, independent, doing well, and we put a valve in you, we care about your quality of life. We want you to do well. Yes, there are options when you become 95 or 100, and 80-year-olds laugh when I tell them that, but I have met so many people back after ten years that the valve was put in ten years ago that are now looking for the next option. We're absolutely not laughing about that. We genuinely are thinking what are the next option for our 80-year-old.

When you talk about lifetime management, I want you to imagine you're a 50-year-old. A 50-year-old comes in and you are replacing their aortic valve. When you replace that, they say, hey, I definitely am not having surgery. I want to have a TAVR because I want to go home the next day and I've heard the valve works really well and everyone is having it and I want that now. What goes through our head? What goes through our head is, okay, 50 years old now, when I bring them back and let's assume these last ten years, they're going to be 60. At 60, they may say the same thing again and maybe I can get one more valve inside there, but if I put one in at 60, we're not going to put three most likely of these TAVR valves in.

You're then going to be 75 years old and you're going to be facing a surgery that's slightly high risk at that time, but say you had done a TAVR at the age of 50 and then when you were – or let's say 60, but you had a – you come back at the age of 65, 70, we do a surgical valve. We then have one to two more options of valve to put back in. When you do those procedures up front, we have to think about what will we do next.



If you're 50, the average life expectancy for someone with valve disease, you're going 76 years old in man, 81 in women. You're thinking, okay, that's then with the technology that was used for this. What if that increases and becomes 85?



We do have to make a plan next time and the TAVR valve may be harder to take care with surgery and the outcomes may not be as good. You want to go to a team and you want to take into account what are my lifetime management options, openminded approach, and do ask the question "What is my next option?"

If this fails, what am I going to do next? What is the risk of going to do next? Is a small upfront risk at any treatment plan now taking account later on? Here's just an example of complexities that we're thinking about. Do we go in? Do we put a valve in? Do we reoperate after that? Do we put another valve in after that? What kind of valve do we put in? Should we do through the legs? Are we taking valve out and then do a surgery and then put – it's complex.

Your team should manage this with you but do go in when you have valve disease managed. No matter how minimally invasive it seems, ask what is my next option? How does this weigh up against an open option? Would there be an advantage towards a minimally invasive approach over surgical, but also ask is there an advantage, and Dr. Fontana is going to talk now, is there an advantage to a surgical approach over minimally-invasive approach and take all that into account, then make sensible decisions while well informed.

Tip #7: Get A Second (Or Third) Opinion



Adam Pick: Moving on to Dr. Gregory Fontana. He is a chairman of cardiothoracic surgery. He is a minimally invasive specialist. He also spends a good amount of time in the hybrid operating suite doing transcatheter work. He specializes in congenital and acquired heart disease. He has done a good amount of investigation specific to clinical trials. Dr. Fontana, thanks for being with us today.



Dr. Gregory Fontana: I think you're starting to see some common themes that are weaving together and I'm hoping it's helpful to those attending. Briefly, I'm a cardiothoracic surgeon. I do cardiac surgery specifically as well as transcatheter valve interventions. One of the few surgeons that's actually trained to do both as a primary operator and it's really an advantage I think at our institution that we have no really bias based on our specialty.

We try to be bias towards the patient's best care and best therapy, which is a theme that is here today with us during this program. I have really enjoyed over the years when I worked in pediatrics and also adult the evolution that has been mentioned of the heart team model where we tap into the expertise and experience of all the members of the various disciplines to help create a plan together with the patient and the patient support system to make sure we get the best result from the therapy that we recommend. I just have a couple tips here before we get to Q&A. First, one is get a second opinion or a third opinion. This was mentioned at the very beginning today by Dr. Johnson.

Heart valve disease can be very confusing. I mean, a valve's function is actually quite simple. It just opens and closes to make sure blood goes in one direction and not the other way and doing it efficiently, but there's a lot of physiology and pathology and related conditions that have been mentioned that make it confusing. I think one of the things that I find myself and I also see with my patients is the more information a patient can be exposed to different opinions, it actually generally makes them less stressed and more enlightened.



As more of the understanding is there, the patient and their support system get more confident in the therapy initially, and also as has been mentioned, in the terms of a lifetime plan.

I would like to just say a cardiologist and a cardiac surgeon certainly should be involved in the evaluation of every heart valve patient. It may be that surgery offers a dramatic advantage in some cases. It can often be done with a small incision. In other cases, clearly transcatheter valve approaches, whether it be aortic, mitral, or now tricuspid, should be done with a transcatheter approach because of the patient's comorbidities or age, for example. There's a big grey area in the middle that really needs to be customized to the patient. At the end of the day, part of that second to third opinion should be a heart team review. If



you don't hear that term or it's not come up in conversation with your providers, please ask them if there's been a heart team that's sat down and reviewed all of your studies and history and collectively have come to recommend the best treatment option for you.

You'll see here we have a myriad of things as mentioned small incision surgery which has been my specialty my whole career is to avoid the sternotomy, as Dr. Ahmed mentioned earlier, splitting open the chest, which actually is gently divided, if you want to be honest about it, but the other options are to do small incisions where the sternum is not divided at all or just very minimally and leave most of the chest and tissues intact. The recovery is actually quite prompt. If it turns out that surgery is recommended to you, you should certainly ask is there a minimally invasive surgical option. We spend a lot of time talking about what kinds of valves.

The two general categories and mechanical and tissue. The good thing about a mechanical valve is it'll last 150 years, but the downside is you're going to require lifelong anticoagulation or blood thinning. Tissue valves are wonderful in that you don't generally require anticoagulation, but they do have a limited durability, maybe it's ten years, or if you're lucky, a bit longer. Then of course, the transcatheter valves, which have really revolutionized our approach to valve or heart disease over the last 20 years or so. It was quite crude in the 2000s and now the technology advanced in such a way that these catheters are small and they're safe and they safely can deliver the new valve or the repair technology in a patient that oftentimes is not under general anesthesia and just sedated.

Tip #8: No Substitute For A Healthy Lifestyle



Dr. Gregory Fontana: Finally, to wrap this up, there's no substitute for a healthy lifestyle. One of the things that I hear very often when patients come back and try to plan ahead of time is they'll come back and say my breathing is much better but I don't have energy, I don't have stamina. Just remember that if you have heart failure or have been slowed down by the heart valve condition that you have, your body becomes deconditioned significantly. It requires a period of reconditioning or rehabilitation. You can really only have the full benefit of the heart valve therapy by optimizing your overall health.

Exercise, everyone can do something, whether that's chair exercises, being in a pool, stationary bikes, walking, keeping active.

The one fundamental that I see with my patients who are older and well, we like to call them "welderly", is that they keep moving. Once people become sedentary, all kinds of consequences of a sedentary lifestyle emerge. Diet and weight control, certainly moderation, anything in moderation. The Mediterranean diet is where we keep coming back to. All of the fad diets have come around.

Smoking cessation, we get you out of heart failure but you continue to smoke, then you have another reason why your shortness of breath may be persistent. Stress reduction strategies, a lot of stress that occurs in medical conditions is manageable with some strategies that you should discuss with your primary care doctor.

Of course, all the other health conditions that come increasingly common as we age, hypertension, diabetes, etc. Then of course, regular follow-up with your cardiovascular team, not just to check your blood pressure and medicine, but to look at your overall cardiovascular health. Am I doing everything I can to optimize the therapy that I've been able to have for my heart valves? I think that's all I have to say today. We'll move on to questions and answers. Thank you, Adam.

Questions & Answers

Nikki asks, "Has any research been conducted on stopping the calcification process of a bicuspid aortic valve? Is there a pill you can take that stops the calcification process of the valve?"



Adam Pick: We are going to move on to a rapid fire questions and answer session as we have now 55 questions and only about 8 minutes. We're going to get to these questions from the patients. If we could ask the panel to answer as succinctly as possible so we can get through as many of them as possible. The first one comes in from Nikki. This is for you, Dr. Johnson. "Has any research been conducted on stopping the calcification process of a bicuspid aortic valve?"

Dr. Heather Johnson: That's a great question, Nikki. We don't have a single medication to be able to slow the progress of the valve calcification, but we do talk about the importance of monitoring your blood pressure, decreasing how much that valve is definitely working. If your team is recommending other therapies in relationship to overall heart health, that will also help the valve.

Cardiac Depression

Rosemary asks, "I had a mitral valve replacement in December and have been struggling with a depressed mood, isolating, etc. My PCP tells me this is an almost universal response to heart surgery. Is there any consensus as to why this happens?"



Adam Pick: Great, thank you, Dr. Johnson. Moving over to Natalie. Rosemary asks, "I had a mitral valve replacement in December and have been struggling with a depressed mood, isolating, etc. My PCP tells me this is an almost universal response to heart surgery. Is there any consensus as to why this happens?"

Natalie Kelley, RN: Thank you, Rosemary, for the question. First of all, if you notice any symptoms of depression or if you're struggling, definitely talk to you medical provider, but certainly discuss that with your heart team and consider if they can prescribe something called cardiac rehab. Cardiac rehab is really a great option for you because it allows you to join other patients and focusing on exercise and return to an active lifestyle. Other considerations would be finding out if your hospital has any kind of support groups. We have one in our facility where they meet regularly and that just allows you to have that comradery with other patients who may have similar experiences to yourself.

Aortic Aneurysms & TAVR

Terry asks, "If you have an ascending aorta repair and down the road you need an aortic valve replacement... Can a TAVR still work (pass through) a repaired ascending aorta?"



Adam Pick: Thanks, Natalie. I don't know if you can see me, but I was smiling ear to ear because cardiac rehab was really the turning point in my recovery that took me out of cardiac depression. Thanks for those comments. Rosemary, I hope that helps you. Moving on to Dr. Ahmed. This is a questions from Terry asks, "If you have an ascending aorta repair and down the road you need an aortic valve replacement, can a TAVR still work pass through a repaired ascending aorta?"

Dr. Mustafa Ahmed: Yes, it can pass through an ascending aorta. You need to look at the aorta before and after and make sure it doesn't need any further work doing itself but a graft itself doesn't prevent that. Assuming the valve is tight, sometimes when an aorta is repaired, it's a leaky valve associated with that and a TAVR for a leaky valve like that may not be the best option, but specific to answer the question, yes, you can pass a TAVR through a repaired ascending aorta.



Adam Pick: Bruce asks, "Is it normal for patients to take coumadin before and after open heart valve surgery due to afib? Does the patient need to take that blood thinner for the rest of their life even if afib is gone?"

Dr. Gregory Fontana: That's a great question, Bruce. Thank you for that. Atrial fibrillation remains, as Adam said, a huge problem in this country. It is often associated with valve disease. If you have open heart surgery, the surgeon should be addressing the atrial fibrillation in two ways. One is potentially doing an ablation to eliminate the rhythm, but most importantly, related to the blood thinner is the removal of the left atrial appendage, this cul-de-sac that's attached to the left atrium that just fibrillates and quivers. That's where blood clots can form. That's why we take blood thinners because that can be associated with stroke. If the surgeon removes or clips the left atrial appendage during that open heart valve surgery, that risk is dramatically reduced. That said, you should work with your cardiologist towards discontinuation of anticoagulation. These days, we've moved from coumadin to other anticoagulants that aren't quite as difficult to manage, but the answer, in short, is there is a potential to discontinue blood thinners after the open heart surgery.

Tricuspid Valve

Irene asks, "I have mild/moderate tricuspid valve regurgitation. Is it serious? Should I see a cardiologist?"



Adam Pick: Irene asks, "I have mild moderate tricuspid valve regurgitation. Is it serious? Should I see a cardiologist?"

Dr. Heather Johnson: Great question, Irene. Yes, it is a great time to see a cardiologist. It's not in a severe stage. Remember, we're saying don't wait. Don't wait for symptoms. Don't wait as far as it becoming severe. You'll be able to walk through what it means as far as how often it's monitored and it's also, as Dr. Fontana highlighted, the importance of a heart healthy lifestyle to really slow progression.

Patient Challenges & Frustrations

Adam asks, "What is the biggest challenge or frustration that patients experience leading up to treatment? And, how you help them overcome that challenge or frustration?"



Adam Pick: Great, thanks, Dr. Johnson. A big question for you, Natalie. It comes in from me. The question is, "What is the biggest challenge or frustration that patients experience leading up to treatment? How can you help them overcome that challenge or frustration?"

Natalie Kelley, RN: This is a big question. I think that the biggest frustration for patients is the new diagnosis whenever the valve disease progresses to that severe range because now it's really impacting their quality of life. Patients now you're being told you have heart valve disease, you're going to the shuffled through all the disappointments, testing, workup, all while being told you get to look forward about making a choice about what operation that you're going to need to fix the issue. As a valve program coordinator, I do get to educate patients about their heart disease. I navigate them through the testing and the workup process. I also empower patients to have a voice in their treatment plan. When I call my patients specifically for that first time, I make sure that they know my name and how to get in touch with me. I think the role of the program coordinator is pivotal to patients and being dedicated to my patients and my hospital helps them overcome frustrations having that central point of contact in your valve program coordinator.

TAVR Complications and Next Steps

John asks, "What are the primary risks involved with TAVR? What percent of TAVR patients have moderate to severe complications? How do heart teams manage complications?"



Adam Pick: I love hearing that you are the intersect and the interface for the patients and the clinical work that's needed. Thank you for that, Natalie. Over to Dr. Ahmed. John asks, "What are the primary risks involved with TAVR? What percent of TAVR patients have moderate to severe complications? How does your team manage those complications?"

Dr. Mustafa Ahmed: Let me try and give a simple answer to a potentially complex question. TAVR itself overall is a safe procedure. The risk depends on the risk of the person going in. If we take a lower risk person, just otherwise healthy, and do a TAVR on them, the risk of the procedure itself should be – you should have a 99% chance of surviving that procedure and doing well. The risk of a pacemaker should be less than 7%. The risk of a leak around the valve should be less than 2% to 3% as significantly. The risk of stroke, which is in my opinion the most feared complication of these procedures, should be less than 1% to 2%.

Of course, as you take sicker and sicker or older and more complex patients in, the risk of those can increase. The risk does decrease depending on experience of the team, depending on number of valves done over time, and quality mechanisms are in place for most places. These are questions which, again, the figures I quoted are okay. There are places with better outcomes than that. There are places with worse outcomes than that. These questions should be asked of anyone wanting to get these valves done or any operation or anything ever done is what is the local experience, what is the risk, can we actually have – can we see some of that data, not just, hey, we do it, great, by the way it works, wonderful.

No, it needs to be what is your published or what is your documented risk of that. That's what I would ask if I went to a place. Lots of people have asked in the questions, "How do we choose where to go?" Lots of really good valve centers exist, but these are the basic questions to ask is what are the complications? How do they compare to the average centers? What is your experience doing this? Because all of that is related to it.



Adam Pick: Great, John, I hope that helped you. I know it helped me. Dr. Fontana, everybody is always thinking about what is the future of valve therapy. Loyal asks, "For aortic valve replacement, what new technologies will be available in the next 15 to 20 years? For example, will we be able to grow a new valve tissue in the lab and have it installed?"

Dr. Fontana:Thanks, Loyal. This is my favorite part of what we do is making advances with technologies and putting in clinical trials to prove we have a better therapy. I'll tell you. I've been doing this for 30 years. We've been talking about growing leaflets using our own tissue my entire career. It really is the holy grail to be able to have a tissue solution that doesn't require blood thinning and also is durable as long as we need it with therapy. I think the most likely next leaflet and valve technology to come out will probably be polymers and there's even some work with nano metals that can last forever. They're so durable that they can last for decades.

There's a lot of work being done in labs right now. I think we'll probably see that before growing our own tissue. There's been a number of technologies now where we take part of the patient's tissue, for example, the sac around the heart, the pericardium, and at the table build a valve with your own tissue. So far those haven't shown to be as durable as the valves that are artificially constructed from either animal tissue or from metals. I am sure that we are going to see things in the next 15 to 20 years that we have never even thought of yet. That certainly has been the case in the past. Stay tuned.

LifeIsGoldenWithEvolutTAVR Campaign



Adam Pick: Thank you for that comment, Dr. Fontana. I want to respect everybody's time. We're coming close to the end of the webinar. Please don't disconnect just yet as we have some closing remarks. We didn't get to some of these questions, but one of the central themes coming out of everybody today, the physicians, Natalie, myself, is this idea of empowerment.

Really, if you think about empowerment, how it looks, it looks a lot of times like the smiling faces on all of these patients that you see here as part of a national campaign that is being launched and management by Medtronic. It's called "Silence Is Not Golden. Life Is." We've already talked today about the under treatment and why, if you have a problem, listen to your body, like Dr. Johnson said. Look at your symptoms. Be open minded. Go and get opinions so that you can have a great outcome specific to your valve therapy. At this new website LifeIsGoldenWithEvolutTavr.com, we asked patients, "What's been your golden opportunity since being treated with TAVR?" It is a fascinating inquiry to see how patients are returning to active living after having a valve therapy. It might be even more empowering and educational for you.

HeartValveSurgery.com Patient Giveaway



Lastly, we are having a Heart Valve Day giveaway that is going on right now. Everybody who was on this webinar is automatically registered in it. The winners announcements are going to be happening soon. We've got a lot of great heartvalvesurgery.com goodies to give away.

As we wrap up, I want to very quickly thank our expert panel, Dr. Johnson, Natalie Kelley, Dr. Mustafa Ahmed, and Dr. Gregory Fontana for being with me today. I really want to thank you, the patients in our community, for coming together and really being a part and being advocates for all of our own healthcare and valve therapies to live the best quality of life that we can.

I'd like to thank you now in advance for doing the survey. On behalf of everybody, we hope you had a great National Heart Valve Disease Awareness Day. Yes, thanks to Medtronic, our sponsor. With that, I wish you all the best. We will be talking to you soon. As we always say here at HeartValveSurgery.com, "Keep on tickin!".

HeartValveSurgery.com Resources for Patients

Since 2006, <u>HeartValveSurgery.com</u> 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.

- <u>Adam's Free Patient eBooks</u> Download 10+ free eBooks about heart valve disease and treatment options for aortic, mitral, pulmonary and tricuspid valves.
- <u>Heart Valve Learning Center</u> Visit the Heart Valve Learning Center to access over 1,000 pages of educational information about valvular disorders.
- <u>Patient Community</u> 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.
- <u>Surgeon Finder</u> Find and research patient-recommended heart surgeons that specialize in heart valve repair and heart valve replacement procedures.
- <u>Heart Hospitals</u> Learn about medical centers that have dedicated teams and resources that specialize in heart valve therapy.
- <u>Adam's Heart Valve Blog</u> Get the latest medical news and patient updates from our award-winning blog.
- <u>Educational Videos</u> Watch over 100 educational videos filmed by the Heart-ValveSurgery.com film team about heart valve surgery.