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**on:** Before we begin our discussion today, I'll introduce our speakers. Dr. Miquel Leal is an te professor in electrophysiology at Emory Health Care. His passion for medical education ntorship lead him to serve as program director of both the Cardiovascular Disease ship Program and the Clinical Cardiac Electrophysiology fellowship program from 2016 until te's contributed as co-author of several clinical practice guidelines issued by the American ssociation, the American College of Cardiology and the Heart Rhythm Society.

# 2:43

**on:** We're also pleased to welcome Ms. Trudie Lobban, the founder of the Arrhythmia e, the AF Association and STARS. All interna

go well, and that that device will help the patient from that point forward. So, any setback, especial

implant, but months or years later, there is still, albeit a very low risk, there is a risk of an infection, and to take prompt action. And to draw this to the attention of the team of doctors or nurses you might be seeing at that time who may not have any training in cardiology. So it almost becomes part of responsibility of the patient, unfortunately, to draw attention to their device. And has the infection spread? Is it affecting my device?

### 10:34-10:42

**Liz Olson:** Dr. Leal, this is a complicated situation, as Trudie's outlined for us, and as you've outlined for us. So how can you create a shared space for patients and providers?

## 10:43-11:15

**Dr. Leal:** So Liz, thanks for bringing this topic up. I think one of the best developments that has taken place in the relationship between a physician, a clinician in general and a patient, in today's day and age is the concept of shared decision-making. For too many years we had paternalistic practices by which a physician would dictate what he or she thought was the best course of care for a patient, and the patient was expected to simply accept it. And here the risks and benefits and essentially play along with what he or she was provided as the best available data.

### 11:16-12:23

**Dr. Leal:** Fortunately, that has evolved significantly. We live in an era of information, an era where patients and families can obtain different sources for knowledge, for information, and I think shared decision-making is all about a truly informed decision about the plan of care and the course of care that a patient should go through. So bringing it into this era of internal devices, bringing it into the spectrum we're discussing here today. From the very beginning, when the decision is made to have a pacemaker or defibrillator implanted in a patient, it is ideal that this conversation took place with a very thorough discussion of the short- and long-term consequences of having and not having the device implanted. So the patients and families, with whatever time they have allowed—sometimes the decisions have to be made a little more quickly, other times that is the opportunity to sit on them for a few days until a final decision can be made—patients and families can truly participate and advocate for their own values and wishes and desires. When it comes to how aggressive or conservative their care will be.

#### 12:24-13:13

**Dr. Leal:** So if an infectious process takes place, which as Trudie correctly alluded to, this is something that we all do not like to see. This is something that is one of the worst possible outcomes because after the implant of a device, you expect that device to serve you well for the entire battery longevity of that device. Be it eight-years, 10-years, 14-years or so. So infectious process happens to interrupt that sequence. It puts a significant curve ball in the narrative. And it's important that patients and physicians, and when I say physicians, I refer to any healthcare professional caring for that patient. So that includes nurses, nurse practitioners, physician assistants, which are every part of the medical ecosystem that we live in. It is important that that

tend to come back worse, because now they have a more systemic approach. It can affect other organs, such as the liver and the brain, the kidneys, the gut, the lungs and many other areas of the body that were not necessarily affected when the infection was first discovered. So these conversations have to be very explicit and very clear. There is enough information. There are enough data published in today's medical literature. So these pieces of information, which are very precious to this discussion, have to be laid out in front of the patient and their families.

### 14:13-14:41

**Dr. Leal:** So, when difficult decisions have to be made, such as for instance, proceeding with the extraction of a system that may have been implanted 10-, 15-, 20-years ago, which is not necessarily a decision without risks themselves. But when those decisions need to be made, it is important that everybody is on board. And to approach this narrative, this dialogue, with a shared-discussion approach, with a shared decision-making approach is certainly in everybody's best interests, especially the patients.

#### 14:42-17:23

**Trudie Lobban:** So shared decision, fantastic! We absolutely endorse it and welcome it. Unfortunately, though, for some health professionals, this is a check box exercise. Did you have a shared decision discussion with your patient? Oh, yeah, I told them they needed a pacemaker. I told them they needed this drug or whatever. So, we need better education and understanding for the patient and the health care professional, and to be able to sit down and discuss. However, time is so short these days. And the number of patients and the time spent with their physician, their nurse, and I agree with Miguel that it needs to be whatever touch point you have throughout your journey with healthcare professionals, every one of them should be having discussions with you. So one of the things we've done at Arrhythmia Alliance in partnership with Mended Hearts was to develop a discussion guide, and that's available to download from our website. And it is for patients to prepare, to educate, to empower them, to have the medical information, but we can give the general education. So, we need to work as one, collaboratively to make sure that the person entering into the system, goes through it understanding what is required, the consequences, and they are able to make those informed, shared decisions. Obviously with guidance and recommendations by their physician, but fully understanding the consequences.

## 18:18-19:00

**Trudie Lobban:** We need to be educating our doctors how to speak with our patients in language that they understand, and for patients not to be scared or anxious to say, "Excuse me, doctor. I don't understand what you just said. I've not heard that word before." And also, to know where they can go away, or they can call us and ask questions that they either ran out of time or didn't like to ask. E

## 21:47-22:26

**Dr. Leal:** So, because the procedure which still deserves a significant degree of respect and reverence as any invasive procedure should. But because this procedure has improved its safety outcomes, and also its performance, its efficiency altogether. It is reassuring to patients, to some degree, to understand that they are signing up for a procedure that has a mortality rate of well less than 1%. It has a risk of major complications that is not significantly different than other

they're being supported by their medical team, and getting through it with them. And for some it has a psychological impact. So you may need to make sure they have all the support in place to

buy a car, you shop around. You go to different dealerships to see what is available. What you want. Healthcare isn't that much different. You want to know that you are accessing the best health care for you, as an individual. So if you hear from the doctor, if you hear from the nurse, if you go to American Heart's [Association] website and you read the same thing, if you come to Arrhythmia Alliance and you read the same thing (maybe in slightly different language, maybe it's more understandable from one than the other) or whatever, it builds your confidence. It builds your knowledge. It builds your awareness.

## 29:50-30:22

Trudie Lobban: And it helps you go right back to that question we had earlier that we discussed. It