

ATTR-CM Podcast, part 2 of 3

- Patty Clemmons, Announcer
- Dr. Amrut Ambardekar
- Dr. Michelle Kittleson
- Patient Richard Hawkins

- Patty Clements: [00:00](#) Hello, and welcome to part two in our three part podcast on ATTR-CM. My name is Patty Clements, and I'm with the communications team at the American Heart Association. Joining me for this discussion is Dr. Amrut Ambardekar, Medical Director, Cardiac Transplant Program, and Associate Professor of Medicine, University of Colorado. Also here is Dr. Michelle Kittleson, Director of Heart Failure Research, as well as post-graduation education and Heart Failure and Transplantation and Associate Professor of Medicine at Smidt Heart Institute, Cedars-Sinai. And ATTR-CM patient Richard Hawkins will also provide his input.
- Patty Clements: [00:34](#) In part one we covered the basics of ATTR-CM. Today, let's look at the causes and the symptoms. So, Dr. Kittleson, what causes ATTR-CM?
- Dr. Kittleson: [00:45](#) Well, due to either genetics or aging, the transthyretin doesn't assemble normally. These abnormal proteins then clump together and shape themselves into what we call amyloid fibrils. These fibrils travel through the bloodstream and are deposited in many organs, including the heart. As fibrils accumulate in the tissue, they thicken and stiffen the myocardium, or wall of the heart, causing a cardiomyopathy and ultimately heart failure.
- Patty Clements: [01:15](#) What are the risk factors for this condition?
- Dr. Kittleson: [01:18](#) So there are two types of the ATTR-CM. Let's talk first about the hereditary form of transthyretin amyloid cardiomyopathy, which is caused by a gene mutation. The risk factors are having a family member with ATTR-CM or heart failure, being over the age of 50, those symptoms can begin anywhere between the ages of 20 and 80, being male, and predominantly this occurs in African-Americans. For the other form, which does not occur from a gene mutation, the wild type transthyretin amyloid cardiomyopathy, the risk factors are being older, above the age of 65, and this also occurs more often in male patients.
- Patty Clements: [02:05](#) So what are the symptoms of ATTR-CM? Dr. Ambardekar, if you could talk about these?

- Dr. Ambardekar: [02:11](#) So the symptoms are like those associated heart failure. The most common symptom is shortness of breath, especially with minimal exertion or when somebody is lying down. The other symptoms usually occur after shortness of breath is already there. The other symptoms can include coughing or wheezing, particularly if lying down, swelling in the feet, ankles, and legs, bloating in the abdomen, confusion or trouble thinking, increased heart rate or palpitations or abnormal heart rhythms. Additional symptoms can include numbness or tingling in the hands and feet, and carpal tunnel syndrome.
- Richard Hawkins: [02:49](#) What was your quality of life as you began to have symptoms? Very simply, breathing became labored and it was again, irregular, it was always experienced at elevation. And you just never knew when a breathing struggle was going to hit, or how long it was going to last. So you just had to sit down and take things easy. I continued to work full time, but my energy level was greatly depleted. I actually hurt in my joints, I actually picked up neuropathy in my hands and feet. I subsequently had a practitioner, neurologist, tell me that was idiopathic or totally unrelated, of unknown origin, but that seemed to hit at the same time.
- Richard Hawkins: [03:42](#) The most difficult issue was the breathing. The problem with the breathing, with the amyloid protein, is very simple. You have a gradual decline with this disease. It's an invasive protein, and it attacks the heart and makes it thicken and stiffen, but at some point, unlike cardiomyopathy which is a much more regular decline, you fall off a cliff. And after my year wait on the transplant list I called my transplant coordinator, Cedars-Sinai, and asked, "Jenna, how much longer do I have? Because I've satisfied my year." She checked her records and said, "You're doing so well that you probably have another year." I hung up over the phone and I was just very disheartened by that, because I had told my bride, "I'm not even going to be here by the first of the year," and that call was around November 1st of 2013.
- Richard Hawkins: [04:45](#) So then I got up the gumption to call Jenna back and I said, "Jenna, I can't even walk up the incline of your parking lot. I'm not going to be here in two months." And she said, "Let's get you in for the tests that measure your heart and lung output." I got put on, I got scheduled for that November 11th, 2013. The numbers were not good. And so they decided to keep me, which advanced my cause, obviously, and they put me in isolation.

- Patty Clements: [05:18](#) What do you think got you through this difficult time? You've been through so much, and then you arrive to this stage and all of this is happening to you. What got you through?
- Richard Hawkins: [05:29](#) My faith. I felt very confident that I was supposed to go through this. The reality of life is you don't get to the beginning of God until you get to the end of yourself. And realizing that you have a short time to live unless you have somebody give you what they call a new heart, it's really an old heart, I asked for a discount. You get a used car, you get a used heart, why can't you bring the price down a little bit? But they would hear nothing of that.
- Richard Hawkins: [06:02](#) But all this to say, what got me through, I was very prayerful. I had many people around the country praying for me. I felt the Lord's peace, the Lord is very real. I could see him open windows and close doors. I mean, too many amazing things happened during my four months there, but not only that, the buildup to the transplant process. I did not have, personally, one second of anxiety. The anxiety was solely absorbed by my bride, who was worried if she'd have somebody to pay her bills. And I saw her weighed down by her worry, and I understand that.
- Richard Hawkins: [06:44](#) I think it's far more difficult on the one giving care than it is on the one being treated.
- Patty Clements: [06:50](#) That's it for today's discussion. Thank you to Dr. Amrut Ambardekar, Dr. Michelle Kittleson for their expert commentary, and Richard, your insight and personal experience is so important to this process, thank you as well.
- Patty Clements: [07:01](#) Remember, this is part two of a three part series. I hope you'll join us next time as we continue with diagnosis and treatment of ATTR-CM. Please visit us at heart.org/attrcm for additional information. The American Heart Association would like to thank Pfizer for funding these educational resources through a grant. Thank you all for your time today.