

## **Do You Have Heart Failure Due to Congenital Heart Disease? This Podcast is For You!**

Announcer: Welcome to the Mayo Clinic Cardiovascular Continuing Medical Education podcast. Join us each week to discuss the most pressing topics in cardiology and gain valuable insights that can be directly applied to your practice.

- Hi, welcome back to "Interview with the Experts" a podcast series from Mayo Cardiovascular Education. My name is Luke Burchill, and I'm the host of this series. And at Mayo Clinic right now, I'm leading the development of the new Heart Failure Care Pathway for adults with heart failure due to congenital heart disease. So now that those introductions are out of way, I wanted to just explain, who is this particular podcast for? This is really for anyone out there, any adults with heart failure due to congenital heart disease. And I just wanted to take some time to answer the common questions that I receive in clinical practice when I'm meeting people like you, someone who might have just been told that their heart function is not normal, it's reduced, or that they have this new diagnosis of heart failure. So we're gonna discuss some of the how's, the whys, the what's, and the whens, and I hope that this is helpful information for you, and that you can take to get the care that you need for you and your heart. So let's start with, how common is this? Heart failure due to congenital heart disease is very common, so we are now seeing up to 1/3 of our patients presenting with this condition called heart failure. So the first thing to know is that you are not alone. This is very common, and in fact, it's now the most common late complication that we are seeing in our adults who had their congenital heart surgery, usually in infancy or childhood. And who are now presenting, decades down the track, with an altered heart function or a clinical diagnosis of heart failure. And we have done some research that has shown that the number of hospitalizations that are occurring among adults with heart failure due to congenital heart disease has increased sharply, just over this last two decades. In fact, there's been almost a 100% increase in the number of adults with heart failure due to congenital heart disease that need to be hospitalized because they've had new onset heart failure. So once again, this is a very common diagnosis. If you've recently found out that you have it, I want you to know that this is something we're seeing commonly and you are not alone. The next question is, why? Why are people who were born with congenital heart disease, they've had everything fixed and repaired, why are they coming in now with these complications? And the answer is, is that those congenital heart defects that you were born with, they have led to changes in the heart's structure and function. And they do predispose, set us up, for heart failure in the future. It's not inevitable that everyone will develop heart failure because they have a diagnosis of congenital heart disease, as I said, roughly 1/3. But it is this underlying history of congenital heart disease which increases the risk. We are looking for any residual defects. So some people have had surgery, but in fact, there were other things that might have been left uncorrected that contribute to late onset changes and reduced heart function. We might have a patient who has valve disease, that their team has known about. It could be a leaky valve or a very tight valve, we call that stenosis. And those valves are causing either a volume, or a pressure load on the heart and its pumps. And over time those pumps don't like that, the function can change, the function becomes reduced, and it can lead to this clinical diagnosis of heart failure. So again, things that were not repaired, or things that we've known about, but have progressed over time. And then we've got a small group of people who are developing new complications. They might have high blood pressure, they might have developed a rhythm abnormality, they might have developed

disease in their coronary vessels, the kind that we see with cholesterol and high blood pressure, they might have had a heart attack. So these are also things that can contribute to later onset heart failure, or reduced heart function in our patients. And when we see someone who comes in to hospital, or comes into the clinic with features of heart failure, our job is to try and understand, why has this patient presented with a clinical diagnosis of heart failure at this time? The big question I'm asked is, "But what is it?" "I don't really even know what it is that you're talking about." So let's just spend some time thinking about, what is heart failure? The first thing I'd like to reassure you of is heart failure does not mean that your heart has failed. That's the biggest source of fear in my patients. When they hear heart failure, they hear, your heart has failed, and that is not the case. What heart failure really means is that there's been a change in heart function, and it has meant that the heart is having difficulty meeting the body's demands. That's the very simple, but I think eloquent definition for heart failure. It's when the heart is not able to keep up with the body's demands. And that might mean that our patients have unexplained intolerance to exercise. They feel more fatigued, they feel out of breath. They might notice swelling is occurring in the legs or in the belly, or they might notice other issues that we see commonly with altered heart function. New onset rhythm changes, or even a stroke can be the way that people present with this altered heart function or heart failure. It is a clinical diagnosis, and what I mean by that is there isn't one single test that leads to a diagnosis of heart failure. It's many tests, and it's your clinical care team putting all those tests together to say, this heart is having difficulty meeting the body's demands, and we see objective evidence that that is the reason why this person is feeling out of breath, or having swelling in their legs, or having other complications like rhythm changes. I also like to emphasize heart failure is not a terminal diagnosis. That's the other concern that patients and families commonly raise when I meet them after just receiving this diagnosis. The belief that being diagnosed with heart failure means that one's days are numbered, and that is not the case for most of the patients that I see who have a diagnosis of heart failure due to congenital heart disease. In fact, most of the time, we can identify some underlying reasons or even triggers for someone to come into hospital. We can correct those things, we can treat those things, and we can get people back to living the full life that they want to live, even though they may have this alteration in their heart function. And notice, I'm saying altered heart function, I'm trying to be careful not to say reduced heart function. Because when we talk about heart failure, there's a couple of different kinds. It's useful, I think for you to know these two kinds because it will determine the kind of treatment that we can provide for you and your heart. The first kind is heart failure with reduced ejection fraction. And in simple terms, I describe that as heart failure due to the pump becoming weak and not pumping so well over time. The other type of heart failure is heart failure with preserved ejection fraction. So on your ultrasound or your echo, we see that the pump actually seems to be pretty brisk and pumping the blood very well on the echo. Actually, the problem in this case is with the heart's ability to relax in between those beats. It turns out that our heart needs to be able to relax in between each beat to let the blood flow in. And that's important for, again, the heart's ability to meet the body's demands. I like to explain this in terms of, imagine an elastic water balloon, when you're filling that with water, it's elastic, it can expand and let that water in. And then imagine trying to fill an eggshell with water under the tap, you know what would happen? That water would splash back in your face, because the eggshell isn't able to relax and let that blood flow in. So that's what we're talking about when we talk about a stiff heart, hearts that are no longer like a balloon and are heading towards being more like a stiff eggshell. So these are the two broad categories. Heart failure with reduced ejection fraction, that's the weak pump. And heart failure with preserved

ejection fraction, that's more the eggshell kind of heart failure. And we now have treatments for both, but different medications are effective for different kinds of alterations in heart function. But I won't go into those treatments today. You'll have to check out some of our other podcasts to hear about the medications. The main thing is for you to know that heart failure is not a terminal diagnosis, it doesn't mean that your life is over. And we have treatments available for whatever kind of altered heart function you might have. So the next question I receive is, where, where should I actually receive care? And the answer to that is you need a team of both adult congenital heart specialists, but also people that specialize in heart failure. And it's important to make sure that those two teams are working closely together. The reality is, is that the adult congenital care pathways have not really been built for people with heart failure. And the heart failure care pathways haven't really been built for people with adult congenital heart disease. And that for our patients has meant that they sometimes fall between the cracks, because neither team feels fully comfortable managing one or the other condition. So it's very important if you've been given a diagnosis of heart failure due to congenital heart disease, that you ask your team, do I have both an adult congenital and a heart failure specialist that are collaborating on my care? Because that's very important for giving you access to the best treatments that are available right now for reduced heart function or heart failure. How do we treat it? What's different about adult congenital heart disease is we have to take that first step back and say, maybe there's something that's been missed, or maybe there's something that needs to be fixed, and that's going to actually improve the heart strength. What kind of things? I mentioned them earlier. Perhaps there was some leftover congenital heart defect that needs to be addressed, it was unrecognized or untreated earlier in life. That's very common in the patients that I see. And those are the patients that I might refer to the surgeon, or to my interventional team for their catheter based procedures. For instance, we might find a hole that can be closed, and that can really help and reset the course for the heart function in that patient. Or I might find that the rhythm changes, so the onset of arrhythmia experienced as palpitations, but our term for that is arrhythmia. We might find that getting control of the rhythm helps to restore the heart function. We might also find that there's been a new onset problem. Remember, I mentioned earlier, someone who's developed coronary artery disease, cholesterol in the coronaries. Or maybe some other complications, high blood pressure. Perhaps they've got disease elsewhere, such as in the kidneys. We want to take that step back and look for all of these other things that could be impacting your heart function, and we want to treat those. At the same time, we do have medications that are specifically targeting altered heart function, whether that be the stiff heart, or the pump that's lost its strength with reduced ejection fraction. So these are the things that I talk to patients about. I hope that this is helpful for you if you've recently been told that you have reduced or altered heart function. If someone has used the term heart failure, I don't want you to despair. I actually want you to feel that there are options, there are treatments available, and we are here to help. Please continue to stay tuned, watch the other podcasts in our series. Knowledge is power, and we'll continue to provide the information you need to take charge of your heart and your heart failure, thank you.