[MUSIC PLAYING]

NASER M. AMMASH: For many years, only up to 15% of all infants born with congenital heart disease will make it to adulthood. But with the advances of care of these patients, the surgeries that we do and how we monitor them after surgery, now 90% to 95% of all infants born with congenital heart disease survive into adulthood.

JOSEPH A. DEARANI: There are actually more adults with congenital heart disease than there are children with congenital heart disease, as a result of all of the wonderful successes that we've had.

NASER M. AMMASH: But there's still a disparity. There's not enough adult congenital heart disease specialists.

JOSEPH A. DEARANI: In the adult age bracket with congenital heart defects, there are generally two categories of patients. There are some that have very subtle findings and they don't become present or obvious until they're an adult. The other group of patients are those that have already been diagnosed and treated, many with surgery earlier on in life, who then develop recurrent problems and require recurrent interventions or surgery.

NASER M. AMMASH: Many patients fall off the radar because they feel good. And they had that surgery and they have been told, you're cured. And there's no cure, predominantly, with congenital heart defect.

JOSEPH A. DEARANI: Valve repairs are going to wear out. Their conduits or connections are going to become narrowed or wear out, or they are going to grow out of what was done when they were younger. And then things will need to be revised when they get older.

NASER M. AMMASH: A structured, long-term plan for these patients is very important because they're here to stay. But we know they're going to have issues.

JOSEPH A. DEARANI: Most of the patients that I operate on, they may not have any symptoms, and we're operating because the imaging is showing a deterioration and we're intervening before it's too late.

NASER M. AMMASH: There are different kind of imaging, from echocardiography to CT to MRI. And depending on congenital heart defect, certain imaging is better than others.

JOSEPH A. DEARANI: The unique thing about the advanced imaging program that we have at the Mayo Clinic, It's not the ability to print the image or reproduce the image on the screen, it's the ability to interpret the image. If you're not familiar what the anatomy would look like after an intervention, particularly surgery, it will look like completely foreign material to you. And so relying on the presence or absence of symptoms is really not a great way to monitor these patients, because symptoms are notoriously absent, or by the time they come frankly present, it's really too late to do anything meaningful or productive.

Probably the most common symptom is something as simple as fatigue. It is not quite as much exercise time. It's not quite as much stamina. It's going to bed a little bit earlier. It's maybe catching a nap a little more frequently than what you used to. It's very, very subtle.

NASER M. AMMASH: If a provider is seeing a patient who has had a congenital heart defect, the thing they should look for are palpitations, feeling of irregular heartbeat, unexplained syncope or passing out, cyanosis, symptoms of heart failure, swelling in the legs, shortness of breath, their belly is getting bigger.

JOSEPH A. DEARANI: When symptoms become present, obvious frank symptoms of shortness of breath or swelling, usually it's way too late. Because by the time symptoms become present in a young adult with congenital heart disease and they have symptoms like that, the cardiac disease is very, very, very advanced. The most common late complication with almost any lesion in the textbook, it's arrhythmias.

Some of them are easily managed with medicines. Some of them require cardiac catheterization to diagnose or treat. Some of them may be related to a structural heart defect that has precipitated the development of the arrhythmia. Because for somebody that's not used to dealing with congenital heart defects, they may not be thinking that it could be a structural problem with the heart that's causing the arrhythmia. So just giving them a prescription for the irregular heartbeat really is not addressing the problem.

NASER M. AMMASH: It's so important, if somebody is seeing a patient with congenital heart defect that they're not trained to take care of, to give a call to somebody who is trained, an adult congenital heart disease specialist, which is now a board certified specialty like heart failure and heart rhythm disease.

When we see a patient in adult congenital heart disease, then I don't see the patient alone. It's a whole team, multidisciplinary team that is really very well integrated into the practice. That's what we do best. Because my patients might have a problem with irregular heartbeat, then we have an adult congenital heart disease specialist who has specialized in arrhythmias and can see them. Another patient might want to get pregnant, so we have a group of physicians, obstetricians, who are really specialists in high risk pregnancy who will come and see the patient with us.

JOSEPH A. DEARANI: When a young woman with a prior history of congenital heart disease is contemplating pregnancy, it is really essential that a specialist in congenital heart disease at the adult level is part of the analysis of whether or not it's appropriate, safe, feasible for this young woman to consider pregnancy. Many times they may need something done in advance to prepare them for a safe pregnancy. It may be surgery.

NASER M. AMMASH: There's more adults with congenital heart disease who are walking the street than kids with congenital heart disease, because things are a lot better. And now with percutaneous approach, with innovation and everything else that we do, it cannot be but better.

JOSEPH A. DEARANI: The next 50 years will be the development and the pursuit of near-perfection with all the operations we do at the lowest possible risk. That is the future of this specialty. It's the advanced imaging and what it provides to the practitioner to plan appropriately.