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Cardiac Sarcoidosis

An immune disease that can reach the heart and pass for heart block, a dangerous rhythm or heart failure.

5–10%
is about how many people with sarcoidosis notice heart symptoms in their lifetime

20–30%
have heart involvement in autopsy studies, so much of it is silent

~1 in 4
cases involve only the heart, with no lung, skin or eye clues

WHAT IT DOES TO THE HEART

Three ways it shows up

1. **Heart block**
Granulomas favor the upper septum, where the wiring runs. Caught while still inflamed, the block sometimes recovers with treatment. Once scarred, it usually needs a pacemaker.

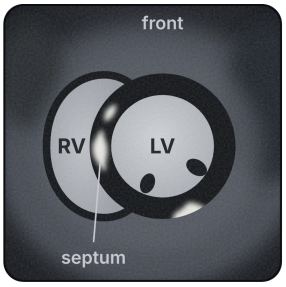
2. **Ventricular tachycardia**
A fast rhythm from the bottom chambers, often 150 to 250 beats a minute, that doesn't pump well. It can cause fluttering, fainting or cardiac arrest.

3. **A weakened heart**
Granulomas spread through the wall and pumping falls. Watch for breathlessness on stairs, swollen ankles and extra pillows at night.

Sarcoidosis makes immune cells clump into tiny **granulomas**. Most people with it are 30 to 60, and anyone diagnosed in the lungs, eyes or skin should be screened for heart involvement.

THE TWO MAIN TESTS

Cardiac MRI and a PET scan



Sarcoidosis
Patchy, mid or outer wall, often the upper septum



Heart attack
One artery's territory, starting from the inside



Amyloid
More uniform, just under the inner surface

Reading the pictures

The heart cut across, as on a cardiac MRI. Contrast dye washes out of healthy muscle and lingers in scar, so 10 to 20 minutes later scar lights up.

- **Healthy muscle stays dark**
- **Scar shows bright white**

A **PET scan** uses a radioactive sugar called FDG to show whether inflammation is active right now or burnt out. That drives treatment, because steroids work on active inflammation and do nothing for old scar.

Ask the question

If you're under 60 with new heart block, an unexplained ventricular arrhythmia or a weakened heart muscle with no clear cause, ask your cardiologist about cardiac sarcoidosis before settling on another diagnosis.

THE PET DIET, TREATMENT AND WHEN TO CALL ARE ON THE BACK

YOUR PLAN

Getting ready, getting treated

THE DAY BEFORE YOUR PET SCAN

the diet is not optional

Eat	Eggs cooked in butter, bacon, avocado, cheese, plain nuts such as walnuts, almonds or macadamia, cottage cheese, unsweetened Greek yogurt, olive oil, and salads with full-fat dressing.
Avoid	Bread, rice, pasta, tortillas, fruit and fruit juice, sweets, desserts, soda, beer and most alcohol, beans and starchy vegetables, and milk, though some imaging centers allow a small amount.
After dinner	Fast for 12 to 18 hours. Water and black coffee are allowed. Follow the diet loosely and the scan can come back unreadable and have to be done again.

TREATMENT, IN THREE LAYERS

Calm the inflammation	Prednisone, starting at 30 to 40 mg a day, at the lowest dose that works. Once a repeat PET shows the inflammation is quiet, usually a few months in, it's tapered slowly over 6 to 12 months, because your body's own steroid production goes sleepy. If needed, methotrexate, azathioprine or mycophenolate can let you use less prednisone. Infliximab is the third-line option if PET still shows inflammation, used cautiously with severe heart failure symptoms.
Protect from dangerous rhythms	A pacemaker gives a backup beat when the signal is blocked. A 2024 AHA statement recommends an ICD after sustained VT or cardiac arrest or with an ejection fraction of 35 percent or lower, and calls it reasonable above 35 percent with fainting, scar on MRI or PET, a need for pacing, or VT set off in an electrophysiology study. When VT keeps happening despite the device, a drug such as amiodarone comes next, and catheter ablation helps when medicine isn't enough.
Support the pumping	A weakened heart gets the four standard heart failure medicines. These are sacubitril-valsartan (or an ACE inhibitor or ARB), a beta-blocker, spironolactone or eplerenone, and an SGLT2 inhibitor. They treat the consequences, while the steroids treat the inflammation.

WHEN TO CALL

Call 911	Chest pain that's severe or doesn't ease within a few minutes, severe shortness of breath at rest, fainting or near-fainting, sustained palpitations lasting more than a few minutes, or an ICD shock. Don't drive yourself, and don't wait it out.
Same day	Call the office for new palpitations that come and go, new lightheadedness, worsening exercise tolerance or new swelling in the legs or ankles.
Within a week or two	Book a visit for questions about medicines, side effects that bother you but aren't dangerous, or diet, exercise, travel and work.

LONG-TERM FOLLOW-UP

Expect visits every 3 to 6 months when stable, an echocardiogram every 6 to 12 months, a cardiac MRI every 1 to 2 years and an EKG at every visit. Inflammation caught before it scars can resolve. Established scar does not, which is the case for catching this early.

READ THE FULL ARTICLE

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cardiac-sarcoidosis

For education only, and not a substitute for advice from your own physician. Sources include the 2024 AHA statement and 2014 HRS consensus on cardiac sarcoidosis, the 2020 American Thoracic Society sarcoidosis guideline, Greulich et al. (JACC Cardiovascular Imaging 2013) and Blankstein et al. (JACC 2014).

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