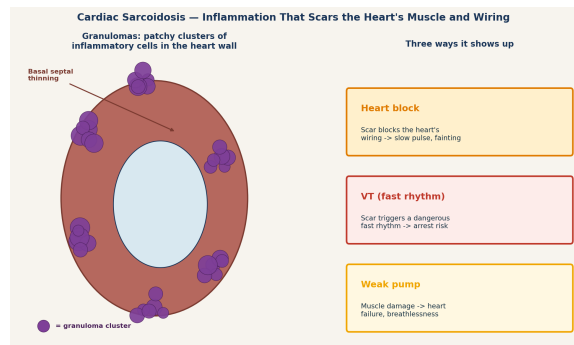


Understanding Cardiac Sarcoidosis

When inflammation scars the heart's muscle and electrical wiring

It can be quiet for years, then cause heart block, a dangerous fast rhythm, or a weak pump. Finding it early changes the outcome.



Online: <https://go.riasalimd.com/sarcoid-guide>

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Names & Terms You Will Hear

Term	Meaning
Cardiac sarcoidosis (CS)	Sarcoidosis that affects the heart. Tiny clusters of inflammatory cells, called granulomas, form in the heart muscle and its wiring.
Granuloma	A small clump of immune cells. In sarcoidosis these clumps form in organs. In the heart they can scar the muscle and block signals.
Sarcoidosis	A whole-body disease where the immune system forms granulomas. It most often hits the lungs and lymph nodes. The heart is involved less often but matters a lot.
Isolated cardiac sarcoidosis	Sarcoidosis found only in the heart, with no clear disease in the lungs or other organs. It can be harder to diagnose.
AV block (heart block)	The electrical signal between the top and bottom of the heart is slowed or blocked. It can cause a slow pulse and fainting.
Ventricular tachycardia (VT)	A dangerous fast rhythm from the lower heart chambers. Scar from sarcoidosis is a common trigger. It can lead to cardiac arrest.
FDG-PET	A scan that lights up areas of active inflammation in the heart. It helps tell 'still inflamed' from 'old scar' and guides treatment.
Cardiac MRI (CMR)	A detailed heart scan that shows scar and damage. It is often the first imaging test when sarcoidosis is suspected.
Immunosuppression	Medicine that calms an overactive immune system. Steroids like prednisone are first. Other drugs are added to lower the steroid dose.
ICD	An implanted defibrillator. It watches the heart and delivers a shock to stop a deadly fast rhythm and prevent sudden cardiac arrest.



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Cardiac sarcoidosis can cause sudden cardiac arrest. If someone collapses and is not responding and not breathing normally: **Call 911. Start Hands-Only CPR. Use an AED.**

Hands-Only CPR: push hard and fast in the center of the chest, about 2 inches deep, 100 to 120 pushes a minute. The beat of the song "Stayin' Alive" is about right.

AED (defibrillator): turn it on and follow the spoken steps. It checks the heart first and will not shock a normal rhythm, so it is safe to use. The PulsePoint app can show the nearest AED.



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What Is Cardiac Sarcoidosis?

- Sarcoidosis is an immune disease. The body forms tiny clusters of inflammatory cells, called granulomas. They can grow in many organs, most often the lungs.
- In cardiac sarcoidosis, these granulomas form in the heart muscle and its electrical wiring. Over time they leave behind scar.
- The heart is involved in about 1 in 20 people with known sarcoidosis (about 5 to 7 percent) by symptoms. But hidden involvement is much more common. Scans and autopsy studies find heart changes in 1 in 4 to 1 in 3 patients in the United States.
- It can be silent for years. When it speaks up, it usually does so in one of three ways: heart block, a dangerous fast rhythm (VT), or a weakened pump (heart failure).
- Some people have sarcoidosis only in the heart, with no lung disease. This is called isolated cardiac sarcoidosis and is easy to miss.
- Because the granulomas form in patches, the damage is uneven. One classic clue is thinning of the wall between the chambers near the top of the heart (basal septum).



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Presentation 1 — Heart Block (Slow or Blocked Signal)

- This is often the first sign. Granulomas scar the heart's wiring, so the signal between the top and bottom chambers is slowed or blocked.
- Symptoms include a slow pulse, lightheadedness, extreme tiredness, and fainting. Some people have no symptoms until the block is advanced.
- Unexplained heart block before age 60 is a major red flag. About 1 in 3 such patients are later found to have cardiac sarcoidosis.
- A pacemaker keeps the pulse steady. Because rhythm risk is high, the device is often a combined pacemaker and defibrillator.
- See our heart block guide for how pacemakers work and what to expect.



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Presentation 2 — Ventricular Tachycardia (Dangerous Fast Rhythm)

- Scar from sarcoidosis can short-circuit the lower chambers and set off ventricular tachycardia (VT), a fast and dangerous rhythm.
- VT can cause palpitations, dizziness, or fainting. At its worst it leads to sudden cardiac arrest.
- This danger exists even when the heart pumps normally. The scar itself is the trigger.
- A defibrillator (ICD) is offered to many patients to stop VT and prevent arrest. Calming the inflammation also lowers the risk.
- If VT keeps happening, a catheter ablation or anti-arrhythmic medicine can target the scar. See our VT and VF guide.



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Presentation 3 — Weak Pump (Heart Failure)

- Patchy damage can weaken the heart muscle so it cannot pump well. This causes heart failure.
- Symptoms include breathlessness (especially lying flat), swelling in the legs, weight gain from fluid, and fatigue.
- Treating the inflammation early can protect or even improve pump function. Old scar is harder to reverse.
- Standard heart failure medicines help the heart work better and ease symptoms.
- See our heart failure guide for daily steps like tracking weight, limiting salt, and knowing when to call.

Active Inflammation versus Old Scar — Why the Difference Drives Treatment

Active inflammation (PET lights up)	Old scar (no PET uptake)
• Disease is hot and ongoing • Immune medicine can help • Steroids are first-line • Repeat PET to track progress	• Damage is cold and fixed • Steroids will not reverse it • Can still trigger VT • Defibrillator may still be needed



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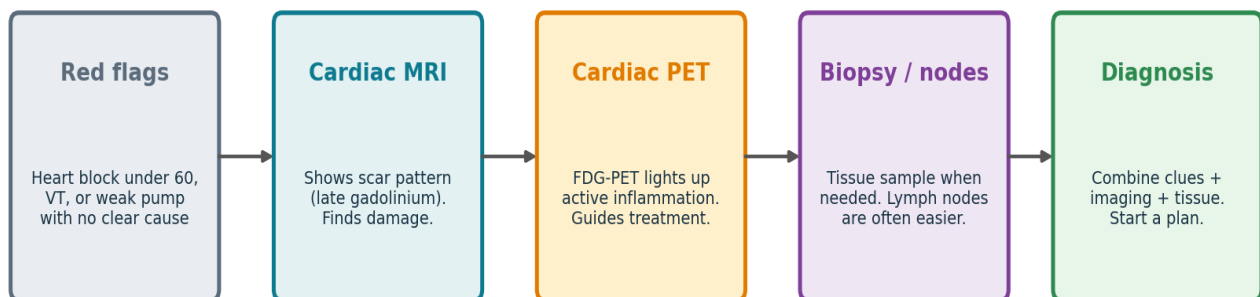
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Why It Matters

- Cardiac sarcoidosis is treatable, but only if it is found. Many cases are missed for years because the early signs look like other heart problems.
- It is a leading cause of sudden cardiac death in younger adults with sarcoidosis. The scar can trigger a deadly fast rhythm with little warning.
- Unexplained heart block in someone under 60 is a major red flag. In studies, about 1 in 3 such patients turned out to have undiagnosed cardiac sarcoidosis.
- Active inflammation responds to immune-suppressing medicine. Old scar does not. That is why finding it early, while it is still inflamed, matters so much.
- The diagram below shows the path we follow to diagnose it: red flags, then cardiac MRI, then a PET scan, and tissue sampling when needed.
- Devices like pacemakers and defibrillators can prevent the worst outcomes while medicine treats the root inflammation.



How we find it: red flags lead to a cardiac MRI for scar, then a PET scan for active inflammation, with tissue sampling when needed.

Hot inflammation versus cold scar: Immune medicine helps only while the disease is active and inflamed. The PET scan lights up this active inflammation. Old, cold scar will not improve with steroids — but it can still trigger dangerous rhythms, which is why a defibrillator may be needed even after the inflammation is gone.



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Risk Factors

Some patients are more likely to develop this condition. Knowing your risk helps your care team take extra precautions.

Risk Factor	Why It Increases Risk
Known sarcoidosis in other organs	Lung or lymph-node sarcoidosis raises the chance the heart is also involved. Anyone with sarcoidosis deserves a heart check.
Younger age with unexplained heart block	Heart block before age 60 with no clear cause is a strong warning sign. It should prompt a search for cardiac sarcoidosis.
Unexplained ventricular arrhythmia (VT)	A dangerous fast rhythm with no clear heart-attack cause can be the first sign that granulomas have scarred the muscle.
African American and Northern European ancestry	Sarcoidosis is more common, and sometimes more severe, in these groups. Risk also varies by family history.
Family history of sarcoidosis	Having a close relative with sarcoidosis raises your own risk. The exact cause is still being studied.
Unexplained drop in heart pump function	A weakened heart muscle with no clear cause (no blocked arteries) can be sarcoidosis hiding as heart failure.



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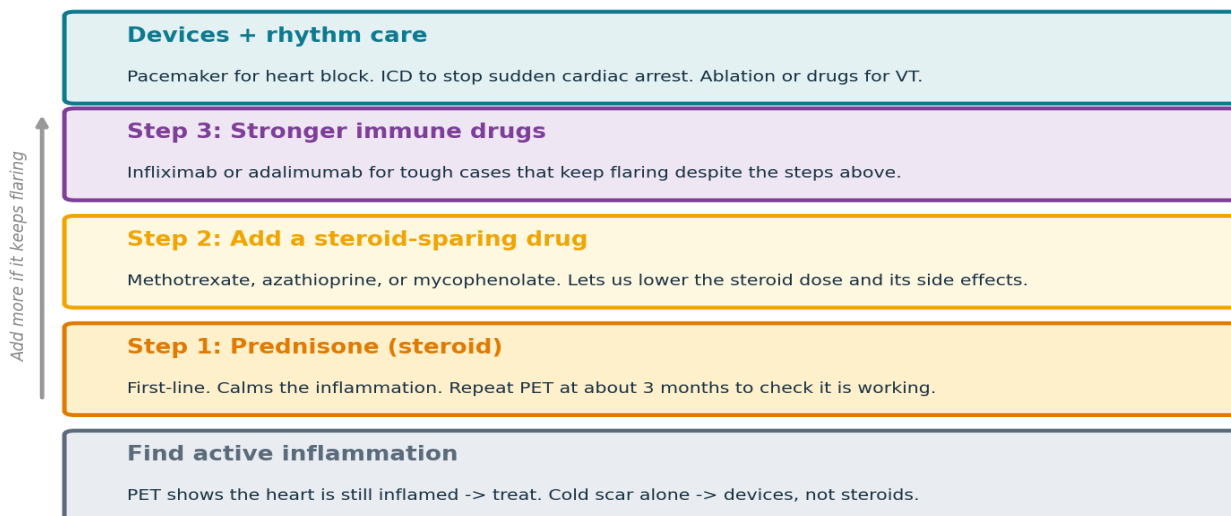
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Treatment Options

- Treatment has two jobs at once: calm the inflammation with medicine, and protect against dangerous rhythms with devices. The diagram below shows the ladder we climb.
- Prednisone, a steroid, is the first-line medicine when scans show the heart is actively inflamed. It is the most proven way to cool the disease down.
- We usually repeat a PET scan at about 3 months to see if the inflammation is settling. If it is, we slowly lower the steroid dose over roughly a year.
- Steroid-sparing drugs such as methotrexate, azathioprine, or mycophenolate are added to many patients. They let us use less steroid and avoid its side effects.
- For tough cases that keep flaring, stronger immune drugs called biologics (infliximab or adalimumab) may be used.
- A pacemaker treats heart block so the pulse stays steady. See our heart block guide for how pacemakers work.
- An implanted defibrillator (ICD) is offered to many patients to stop a deadly fast rhythm. Even with normal pump function, the scar itself raises arrest risk.
- If VT keeps happening, anti-arrhythmic medicine or a catheter ablation can target the scar that triggers it. See our VT and VF guide.
- Care is best given by a team: a cardiologist, an electrophysiologist (rhythm doctor), and often a sarcoidosis or lung specialist working together.



The treatment ladder. We treat active inflammation with steroids first, add steroid-sparing drugs, and use devices to guard against dangerous rhythms.



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Devices and Rhythm Care — Matching the Problem to the Fix

Problem	What it does	Usual fix
Heart block (slow signal)	Slows the pulse; can cause fainting	Pacemaker (often with defibrillator built in)
VT (dangerous fast rhythm)	Can cause arrest with little warning	Defibrillator (ICD); ablation or drugs if it recurs
Weak pump (heart failure)	Breathlessness, swelling, fatigue	Heart failure medicines; sometimes a special pacemaker (CRT)
Active inflammation on PET	Ongoing damage to muscle and wiring	Steroids plus steroid-sparing drugs (not a device)



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Comfort Measures at Home (No Medication Needed)

These simple steps support healing and ease symptoms. Use them alongside any medication your doctor prescribes.

- Take your immune-suppressing medicine exactly as prescribed. Do not stop steroids suddenly on your own. Stopping too fast can be dangerous.
- Keep every imaging and device follow-up. PET scans tell us whether to raise or lower your medicine. Device checks make sure your pacemaker or ICD is working.
- Weigh yourself daily if you have any heart failure. Sudden weight gain can mean fluid is building up. Tell us early.
- Limit salt to ease fluid retention if your pump is weak. Your care team can give you a target.
- Ask about bone health, blood sugar, and infection risk while on steroids. Simple steps like calcium, vitamin D, and vaccines help.
- Wear or carry medical ID that lists cardiac sarcoidosis and any device. It helps in an emergency.
- Tell every doctor about your ICD before any surgery or MRI. Some equipment needs special settings.



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Risks, Benefits, and Alternatives

Every choice has trade-offs. Use this table to start the shared decision conversation.

Option	Risks	Benefits	Alternatives
Steroids (prednisone) for active inflammation	High blood sugar, weight gain, mood changes, bone thinning, infection risk. Needs slow taper.	Calms active inflammation. The most proven way to protect heart muscle and wiring. Can improve heart block and pump function if caught early.	Steroid-sparing drug first (rarely). No treatment (only if scans show old scar with no active inflammation).
Steroid-sparing drug (methotrexate, azathioprine, mycophenolate)	Liver or blood-count changes, infection risk. Needs regular blood tests. Slow to take effect.	Lets us lower the steroid dose and its side effects. Helps keep inflammation controlled long term.	Higher steroid dose alone (more side effects). Biologic drug (stronger, for resistant cases).
Pacemaker for heart block	Small procedure risk: bleeding, infection, lead problems. Device checks for life.	Keeps the pulse steady. Prevents fainting and very slow heart rates from heart block.	Medicine alone (does not fix block). Watchful waiting (risky if block is advanced).
Defibrillator (ICD) to prevent sudden arrest	Procedure risk; rare inappropriate shocks; device checks. Lead and battery upkeep.	Stops a deadly fast rhythm. Major protection against sudden cardiac arrest, even when the pump looks normal.	Medicine alone for rhythm (less reliable). Wearable defibrillator vest (temporary bridge).
Catheter ablation or drugs for recurring VT	Procedure risk; VT may come back; drug side effects. Often done with steroids on board.	Reduces dangerous fast-rhythm episodes and ICD shocks. Targets the scar that triggers VT.	ICD plus medicine only (if ablation is too risky). Increasing immune therapy first (calm inflammation).



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Common Misconceptions

Myth	Reality
Sarcoidosis is only a lung disease, so my heart is safe.	Sarcoidosis can affect many organs, including the heart. Even people whose lungs look fine can have it in the heart. Anyone with sarcoidosis deserves a heart check, and some people have it in the heart alone.
My heart pumps normally, so I am not at risk for sudden problems.	Cardiac sarcoidosis can cause a deadly fast rhythm even when the pump looks normal. The scar itself is the trigger. That is why a defibrillator is offered to many patients with normal pump function.
If a scan shows scar, steroids will reverse it.	Steroids calm active inflammation. They do not erase old scar. This is why we use PET scans to find active inflammation and treat while there is still something to save.
A pacemaker fixes cardiac sarcoidosis.	A pacemaker treats the slow rhythm from heart block. It does not treat the inflammation or stop a fast, dangerous rhythm. Most patients need immune medicine and often a defibrillator too.
Heart block in a young person is usually just bad luck.	Unexplained heart block before age 60 is a red flag. In studies, about 1 in 3 such patients had undiagnosed cardiac sarcoidosis. It deserves a careful search, not a shrug.
Once I feel better, I can stop the medicine.	Stopping immune medicine too soon can let the inflammation flare back. Steroids in particular must be lowered slowly. We use scans and follow-ups to decide when and how to taper.
Cardiac sarcoidosis is always fatal.	It is serious, but it is treatable. People who are found early and treated with medicine plus the right device can do well for years. Finding it early is the key.



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Possible Complications

Knowing what can go wrong helps you spot problems early. Most complications are uncommon, especially with treatment.

Where / What	What Can Happen
Heart's wiring (conduction system)	Granulomas and scar can block the signal between the top and bottom of the heart. This causes heart block, a slow pulse, and fainting. It is often the first sign and may need a pacemaker.
Lower chamber rhythm (ventricles)	Scar can trigger ventricular tachycardia (VT), a dangerous fast rhythm. VT can lead to sudden cardiac arrest. It is a main reason a defibrillator is offered.
Heart muscle (pump function)	Patchy damage can weaken the heart muscle and cause heart failure. Symptoms include breathlessness, swelling, and fatigue. See our heart failure guide for day-to-day care.
Right side of the heart and lungs	Lung sarcoidosis and a weakened heart can raise lung blood pressure. This strains the right side of the heart and worsens breathlessness.
Sudden cardiac arrest	The most feared complication. A deadly fast rhythm can stop the heart with little warning. Defibrillators and CPR/AED readiness save lives. See the callout in this guide.
Steroid and immune-drug side effects	Treatment itself can cause high blood sugar, bone thinning, weight gain, and infection risk. We watch for these and use steroid-sparing drugs to lower the dose.



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Points to Know

If you remember nothing else, remember these key points.

- Cardiac sarcoidosis is inflammation that scars the heart muscle and wiring. It is treatable when found early.
- It usually shows up in one of three ways: heart block, a dangerous fast rhythm (VT), or a weak pump (heart failure).
- Unexplained heart block before age 60 is a major red flag. About 1 in 3 such cases turn out to be cardiac sarcoidosis.
- Diagnosis uses cardiac MRI to find scar and a PET scan to find active inflammation. Tissue is sampled when needed.
- Prednisone is first-line when the heart is actively inflamed. Steroid-sparing drugs are added to lower the dose.
- A defibrillator (ICD) is offered to many patients to prevent sudden arrest, even when the pump looks normal.
- Repeat PET scans tell us if the inflammation is settling, so we know when to lower medicine.
- Care works best with a team: a cardiologist, a rhythm specialist, and often a lung or sarcoidosis doctor.



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When to Call Us - and When to Call 911

If you are not sure, call. We would rather hear from you twice than miss a real problem.

- Fainting, near-fainting, or a blackout spell — call us today; if someone collapses and is unresponsive, call 911.
- A very slow pulse, with dizziness or extreme fatigue — call us today (possible heart block).
- A racing, pounding, or irregular heartbeat that does not settle — call us today (possible VT).
- New or worsening shortness of breath, especially lying flat — call us today.
- Sudden swelling of the legs, ankles, or belly, or fast weight gain — call us this week.
- Your ICD delivers a shock — call us right away; if you feel unwell or get repeated shocks, call 911.
- Fever, cough, or signs of infection while on immune medicine — call us promptly.
- Chest pain or pressure — call 911.

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Trusted Resources

The links below are the trusted resources Dr. Ali used to write this guide and that he recommends you visit for more information. Each is a clickable link in the digital version and a Short.io tracked URL on the printed version.

- [Cleveland Clinic — Cardiac Sarcoidosis](#) - Patient-friendly overview of granulomas in the heart, rhythm and block risk, and treatment.
- [Mayo Clinic — Cardiac Sarcoidosis Clinic](#) - Explainer on multidisciplinary diagnosis and care for the condition.
- [American Heart Association — Heart Failure](#) - AHA patient hub on heart failure, which cardiac sarcoidosis can cause.
- [Foundation for Sarcoidosis Research](#) - Patient support, education, and research updates for all forms of sarcoidosis.
- [Heart Block & Pacemakers — our guide](#) - How heart block works and what a pacemaker does.
- [VT and VF — our guide](#) - Our guide to ventricular tachycardia, defibrillators, and ablation.
- [Heart Failure — our guide](#) - Day-to-day care for a weakened heart pump.
- [Defibrillators \(ICD & CRT\) — our guide](#) - How an ICD watches your heart and stops a deadly rhythm.
- [Cardiac PET — our guide](#) - What a PET scan shows and what to expect.
- [Cardiac MRI — our guide](#) - What a cardiac MRI shows and what to expect.



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Sources Used to Build This Guide

Every recommendation in this guide is grounded in one or more of the studies, guidelines, or trusted resources below. Short links are tracked so Dr. Ali can see which references patients are reading; nothing personally identifying is captured.

- [AHA Scientific Statement — Diagnosis and Management of Cardiac Sarcoidosis \(2024\)](#) [Guideline]
Current AHA statement on imaging (FDG-PET/CMR), immunosuppression, and ICD decisions.
- [2014 HRS Expert Consensus on Arrhythmias Associated With Cardiac Sarcoidosis](#) [Guideline]
Foundational diagnostic criteria and the device/arrhythmia management framework.
- [Cleveland Clinic — Cardiac Sarcoidosis](#) [Clinical]
Patient overview of inflammatory granulomas in the heart, block/arrhythmia risk, and treatment.
- [Mayo Clinic — Cardiac Sarcoidosis Clinic Overview](#) [Clinical]
Patient-facing multidisciplinary-care explainer for the condition.



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About This Guide

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Version: 2026-08-15

Reviewer note: Reviewed: Cleveland Clinic, Mayo Clinic, AHA 2024 statement, 2014 HRS consensus. This guide adds a CMR-PET-biopsy diagnostic flow diagram, a tiered treatment-ladder diagram, per-presentation deep dives (heart block, VT, weak pump), a severity-tinted device table, and a Call-911/CPR/AED arrest callout — content most patient pages omit.

Disclaimer

This guide is for educational purposes only and does not replace medical advice from your physician. Recommendations may not apply to every patient. Always follow the specific instructions of Dr. Ali and your care team. In an emergency call 911 or go to the nearest emergency department.



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