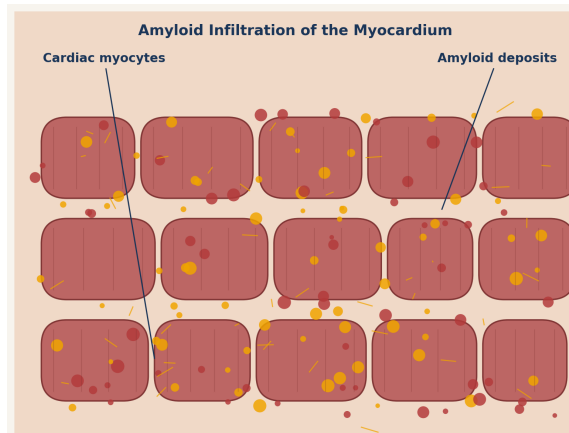


Understanding Cardiac Amyloidosis

An abnormal protein builds up in the heart and makes it stiff

It can be treated — but only if it is found.



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

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Names & Terms You Will Hear

Term	Meaning
Cardiac amyloidosis	An abnormal protein called amyloid builds up in the heart muscle, making it stiff and thick.
ATTR amyloidosis	Transthyretin amyloidosis — the most common cardiac type. Two forms: wild-type (age-related) and hereditary (gene change).
AL amyloidosis	Light-chain amyloidosis. Comes from abnormal bone marrow cells. Less common but moves fast — a blood doctor (hematologist) leads care.
Transthyretin (TTR)	A protein made by the liver. When TTR folds the wrong way, it builds up in the nerves and the heart.
Senile cardiac amyloidosis	An old name for wild-type ATTR. Doctors no longer use this term.
Restrictive cardiomyopathy	A stiff-heart pattern. Amyloid makes the heart walls thick and hard to fill, even though the squeeze (ejection fraction) stays normal at first.



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What Is Cardiac Amyloidosis?

- Amyloid is a protein that folds the wrong way. It stacks into fibers and builds up in organs. In the heart, it makes the muscle stiff and thick.
- There are two main cardiac types: **ATTR** (transthyretin) and **AL** (light chain). They can look alike on imaging, but they are different diseases with different treatments.
- **ATTR-wild-type** is the most common form. It mainly affects men over 70. For a long time, doctors missed it as normal aging.
- **ATTR-hereditary** runs in families. The V122I gene change is more common in Black patients. The V30M change is more common in patients from Portugal, Sweden, or Japan.
- **AL** comes from abnormal cells in the bone marrow. It moves fast and needs urgent care from a blood doctor (hematologist).
- Many patients have several **red flags** at once: carpal tunnel in both hands, lower-back spinal stenosis, biceps tendon rupture, a low-voltage EKG, thick heart walls on echo, and unexplained heart failure with a normal squeeze (preserved ejection fraction).



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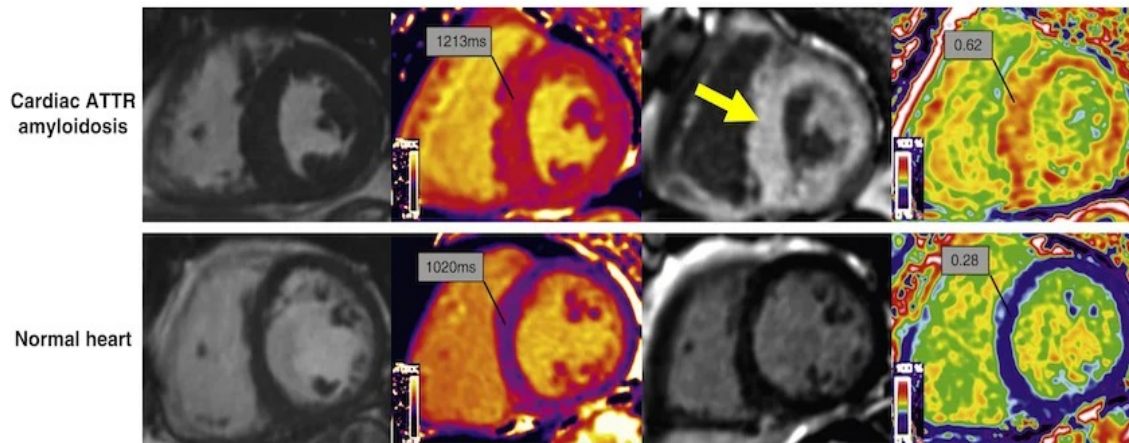
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Why It Matters

- Without treatment, cardiac amyloidosis leads to severe heart failure, abnormal heart rhythms, and early death.
- Modern treatment helps. **Tafamidis** for ATTR reduced deaths by 30% in the ATTR-ACT trial. Quality of life also improves.
- Amyloidosis is often **missed**. A bone scan (PYP scan) plus a few blood and urine tests can confirm ATTR without a biopsy in most cases.
- AL amyloidosis must be ruled out first. Its drugs are not the same as ATTR drugs — the two types need separate care paths.
- Family members of patients with hereditary ATTR may benefit from gene testing.



Heart MRI side-by-side — top row is ATTR amyloidosis, bottom row is a normal heart. Each row shows three scans: late gadolinium dye pattern (left), T1 map (middle, 1213 ms in amyloid vs 1020 ms normal — much higher), and extra-cell volume map (right, 0.62 amyloid vs 0.28 normal — more than double). The yellow arrow marks the amyloid area. A heart MRI can confirm the diagnosis without a biopsy in most cases.



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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
Age over 65	Wild-type ATTR becomes much more common with age. Up to 25% of men over 85 have some amyloid in the heart.
Male sex	ATTR-wild-type is far more common in men than in women.
Family history of amyloidosis	Hereditary ATTR is passed down through families. If a parent has it, close relatives should be tested.
Black or Caribbean ancestry	The V122I gene change is found in about 3–4% of Black Americans. It raises the risk of ATTR heart disease.
Carpal tunnel in both hands	This often appears years before heart symptoms in ATTR. It is a major warning sign.
Lower-back spinal stenosis	Amyloid deposits in the spine are common with ATTR.
Biceps tendon rupture without injury	Also called the "Popeye sign." A strong clue for ATTR.
Multiple myeloma or MGUS	These blood cell disorders raise the risk of AL amyloidosis.
Thick heart walls with normal squeeze	If an echo shows walls thicker than 14 mm but a normal squeeze, amyloid should be ruled out.



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Treatment Options

- **ATTR — tafamidis (Vyndaqel/Vyndamax):** keeps the TTR protein stable so it cannot build up. One pill a day. The main drug for ATTR heart disease.
- **ATTR — patisiran (Onpattro) and inotersen (Tegsedi):** gene-blocking drugs. Approved for ATTR nerve damage and now being studied for the heart.
- **ATTR — acoramidis:** a newer TTR drug. The FDA approved it in 2024 for ATTR heart disease.
- **AL — blood doctor (hematologist) leads care:** drugs such as CyBorD and daratumumab are used. Some patients get a stem-cell transplant. AL needs a bone marrow biopsy and blood-cell workup.
- **Heart failure care:** water pills (diuretics) help with swelling but must be used with care. Amyloid patients respond strongly to even small fluid shifts.
- **Drugs to avoid:** digoxin can build up to toxic levels. Beta-blockers at high doses, verapamil, and diltiazem can weaken the pump in amyloid. ACE inhibitors can drop blood pressure too far if the nerves are also affected.
- **Atrial fibrillation (AFib):** very common in amyloid. A blood thinner is usually needed to lower stroke risk.
- **Gene counseling:** advised for families with hereditary ATTR.



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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
Tafamidis (ATTR heart)	Very costly without insurance. Can cause mild diarrhea. Does not treat nerve damage.	Cut deaths by 30% in the ATTR-ACT trial. Slows the disease. One pill a day. Well tolerated.	Acoramidis (newer TTR drug). Supportive care only.
Acoramidis (ATTR heart)	Costly. Less long-term data than tafamidis.	Holds TTR more firmly than tafamidis. Trial data show fewer heart events.	Tafamidis. Gene-silencing drugs. Supportive care.
Bone scan (PYP) workup	Small radiation dose. Can give a false-positive result in AL amyloidosis.	Confirms ATTR without a biopsy in most patients. Safe and non-invasive.	Heart muscle biopsy (endomyocardial biopsy). Cardiac MRI.
Heart muscle biopsy (endomyocardial biopsy)	An invasive procedure. Small risk of bleeding, abnormal heart rhythm, or perforation.	Gives a definite tissue answer when imaging tests are not clear.	PYP bone scan. Cardiac MRI. Rarely needed for ATTR today.



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Common Misconceptions

Myth	Reality
"Amyloidosis is rare — it can't be me."	Wild-type ATTR is more common than people think. Up to 13% of patients with heart failure and a normal squeeze may have amyloid.
"My heart squeeze is normal — it can't be amyloidosis."	Cardiac amyloid usually keeps the ejection fraction (squeeze) normal until late in the disease. Thick walls with a normal squeeze is the classic sign.
"My carpal tunnel and back problems are not related to my heart."	Carpal tunnel in both hands, spinal stenosis, and biceps tendon rupture are outside-the-heart warning signs for ATTR. They can appear years before heart symptoms.
"There is nothing you can do for amyloidosis."	There is now. Tafamidis cuts deaths from ATTR-CM. AL amyloidosis can be treated by a blood doctor. Finding it early helps.
"If it is genetic, my children will get it too."	Hereditary ATTR is passed down through families, but not everyone who carries the gene change gets the disease. Treatment also exists. Gene counseling helps families plan.
"My bone scan was positive — I need a heart biopsy."	If blood and urine tests for light chains are normal and the PYP scan is grade 2 or 3, most patients get an ATTR diagnosis without a biopsy.



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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 failure	The stiff heart cannot fill well. Shortness of breath and swelling get worse over time.
Atrial fibrillation (AFib)	Very common with amyloid. Stroke risk is high — a blood thinner is usually needed.
Slow heart rhythm / heart block	Amyloid can slow or block the heart's electrical signals. A pacemaker may be needed.
Orthostatic hypotension	A sudden drop in blood pressure when standing up — a sign that the nerves are also affected.
Aortic stenosis overlap	Amyloid often occurs together with a tight aortic valve. Both may need to be treated.
Nerve damage — neuropathy (ATTR)	Numbness, pain, or falls. If this develops, ask about gene-blocking drugs.
Kidney damage (AL more often)	AL amyloid can cause large amounts of protein to leak into the urine. A kidney doctor should follow up.



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Points to Know

If you remember nothing else, remember these key points.

- Cardiac amyloidosis can be treated — finding it early matters most.
- Warning signs: carpal tunnel in both hands, lower-back stenosis, biceps tendon rupture, or a thick heart with a low-voltage EKG.
- ATTR and AL look alike but are different diseases. Always test for AL (light chains) first.
- A bone scan (PYP) is the main non-invasive test for ATTR once AL is ruled out.
- Tafamidis cuts ATTR-CM deaths by 30%. Acoramidis is a newer approved option.
- Use water pills carefully. Avoid digoxin and verapamil. Take a blood thinner for AFib.
- Hereditary ATTR runs in families. Close relatives may need gene testing.



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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.

- **Call 911** for fainting, severe shortness of breath, or chest pain that does not go away.
- **Call our office** if you gain more than 3 pounds in 2 days or 5 pounds in a week.
- **Call our office** if your legs swell up or your breathing gets worse with activity.
- **Call our office** if you feel dizzy or lightheaded when you stand up. This is common in amyloidosis.
- **Call our office** if you get new numbness, tingling, or pain in your hands or feet.
- **Call our office** before starting beta-blockers, verapamil, diltiazem, or digoxin. These can be harmful in amyloidosis.
- **Call our office** if a family member is found to have hereditary ATTR. Gene counseling can help your family plan ahead.

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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.

- [Amyloidosis Foundation](#) - Patient community and education.
- [AHA — Cardiac Amyloidosis](#) - Patient-facing overview from American Heart Association.
- [Cleveland Clinic — Cardiac Amyloidosis](#) - Comprehensive overview.
- [Mayo Clinic — Cardiac Amyloidosis](#) - Diagnosis and treatment overview.
- [NHLBI — Amyloidosis](#) - Federally sourced patient information.



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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: Cardiac Amyloidosis \(2020\)](#) *[Scientific Statement]*
Definitive overview of ATTR and AL cardiac amyloidosis; diagnostic algorithm and red-flag findings.
- [ACC Expert Consensus: Diagnosis and Treatment of Cardiac Amyloidosis \(2023\)](#) *[Guideline / Consensus]*
Current US treatment algorithm including tafamidis, patisiran/inotersen, and the gene-silencing era.
- [ATTR-ACT trial \(tafamidis for ATTR cardiomyopathy\)](#) *[Randomized Trial]*
Pivotal RCT showing tafamidis reduces all-cause mortality and cardiovascular hospitalizations in ATTR-CM.
- [Mayo Clinic — Cardiac Amyloidosis](#) *[Patient Education]*
Plain-language symptom and diagnosis overview.
- [Amyloidosis Foundation](#) *[Patient Advocacy]*
Patient community, support resources, and education materials.
- [NHLBI — Cardiac Amyloidosis](#) *[Patient Education]*
Federal patient-education resource.
- [Maurer MS et al. Genotype-Specific Treatment Outcomes in ATTR-ACT.](#) *[Subanalysis]*
Wild-type vs hereditary ATTR response to tafamidis — informs misconceptions about hereditary disease.
- [ATTR Amyloidosis Patient and Caregiver Guide \(CCF\)](#) *[Patient Education]*
Comprehensive plain-language overview from a major academic center.



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About This Guide

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Reviewer note: Reviewed against Mayo Clinic, Cleveland Clinic, AHA, and NHLBI amyloidosis pages. This guide adds: a clear ATTR vs AL plain-language comparison, the current tafamidis and gene-silencing treatment options, and the warning signs that should prompt an evaluation.

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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