

Understanding Cardiac Amyloidosis



You have been diagnosed with cardiac amyloidosis. This sheet will help you better understand the disease. Knowing more about it can help you make the best decisions about your care. If you have any questions or concerns, talk with your healthcare provider. They are here to help.

How to say it

KAHR-dee-ak am-eh-loy-DOH-sihs

What is cardiac amyloidosis?

When you have amyloidosis, your body makes too much of certain proteins. These proteins build up and clump together, making a waxy substance called amyloid. These clumps of amyloid can impair how your body works and damage parts of it.

There are many types of amyloidosis. Some kinds are systemic. That means they affect many parts of the body. Other types affect only 1 part of the body, such as an organ like the liver or heart. When amyloid builds up in the heart, the disease is called cardiac amyloidosis. It can lead to heart failure, an irregular heartbeat, and other problems.

What causes cardiac amyloidosis?

The exact cause of cardiac amyloidosis is often unknown. But it tends to occur in older adults. In some cases, it can be passed down in families. A change in a gene may also cause an overproduction of proteins.

Cardiac amyloidosis may also be caused by other diseases. Some of these include:

- Multiple myeloma
- Rheumatoid arthritis
- Bowel disease
- Psoriatic arthritis

What are the symptoms of cardiac amyloidosis?

The symptoms of cardiac amyloidosis may vary from person to person. And your symptoms may get worse as amyloid builds up in your heart. You may have symptoms such as:

- Shortness of breath with activity or at rest
- Fatigue
- Swelling of the legs or belly
- Lightheadedness or fainting
- Irregular heartbeat
- Chest pain (angina)

If amyloid is also building up in other parts of your body, you may have:

- Weight loss
- Tingling or numbness in your arms or legs
- Nausea
- Constipation
- Lack of appetite

How is cardiac amyloidosis treated?

Your healthcare provider will talk with you about your treatment options. They will depend on things like your age, your overall health, and your preferences. They will also depend on the type of amyloidosis you have and the extent of the disease. Together, you and your healthcare provider can decide what treatment is best for you.

Your treatment options may include:

- **Diuretics.** Cardiac amyloidosis often leads to heart failure. So your healthcare provider may give you a diuretic. This medicine can help reduce fluid buildup and swelling in the body which can ease the work on your heart.
- **Medicines that target amyloid.** Your provider may prescribe medicines to help lower or get rid of amyloid in your body. These can be used for some types of the disease.
- **Other treatments.** If another health problem is causing the cardiac amyloidosis, treating that problem may help. For instance, you may have chemotherapy if multiple myeloma is causing the disease.
- **Heart transplant.** If the heart is badly damaged, it may need to be replaced. This surgery is often done after all other treatments have been tried.

What problems can cardiac amyloidosis cause?

Cardiac amyloidosis can lead to other health problems. These are called complications. They may include:

- Heart failure
- Irregular heartbeat
- Heart attack
- Nerve problems
- Kidney problems
- Skin changes

What else can you do to feel better?

Work closely with your healthcare providers. They are here to support you in your treatment decisions. It's also helpful to take an active role in your care, such as:

- Keeping all appointments
- Getting regular screenings or other tests
- Taking your medicines as directed
- Asking about clinical trials

You can also find support through the [Amyloidosis Foundation at amyloidosis.org](https://amyloidosis.org).

Call

If at any time you have the following symptoms, call right away:

- Trouble breathing
- Severe chest pain
- Loss of consciousness

When to call your healthcare provider

Reach out to your healthcare provider right away if you have any of these:

- Fever of 100.4°F (38°C) or higher, or as directed by your provider
- Symptoms that don't get better or get worse, such as angina
- New symptoms

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