SCAN ME

Questions to Ask Your Doctor

- What caused my AL amyloidosis?
- How severe is my AL amyloidosis?
- Do I need additional testing?
- What complications could arise from my AL amyloidosis?
- Are there medications available to manage my disease?
- What side effects can I expect from these medications?
- What other treatment options are there?
- Will my insurance cover my treatment?
- How can I prevent my AL amyloidosis from worsening?
- Are there lifestyle changes I should I make that would be helpful?
- What symptoms should I contact you about or seek emergency care for?

Contact Us

If you would like to receive support or need more information, please contact us at:

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Living With AL (Amyloid Light Chain) Amyloidosis

The Mended Hearts, Inc.

Discussion Guide for Patients & Caregivers

What is AL Amyloidosis ?

Amyloid light chain (AL) amyloidosis is a rare, severe, progressive, disease. There is a buildup of abnormal protein called amyloid in your organs, causing them to not work properly. The amyloid protein deposits can occur throughout your body but is most common in the heart and kidneys.

There are cells in your bone marrow, known as plasma cells, that are part of your normal immune system. However, in AL amyloidosis these cells malfunction and start producing too much of the abnormal amyloid. When amyloid builds up in the heart it is called cardiac amyloidosis, a type of cardiomyopathy. The heart muscle becomes thick, stiff, and weakened, leading to heart failure, abnormal heart rhythms and valvular disease.

Signs and Symptoms

Cardiac:
Heart palpitations
Shortness of breath or difficulty breathing
Chest pain

Kidney:
Urine is more bubbly or foamy than usual
Less frequent urination
Needing to urinate during the night

Stomach or intestinal:
Loss of appetite
Weight loss
Bloating
Constipation
Diarrhea

Other:
Light-headedness, dizziness, or fainting, especially when standing up
Purple rash around eyes or eyelids
Enlarged tongue
Numbness or tingling in hands, fingers or feet
Swelling in legs or ankles
Weak legs
Easy bruising or bleeding

What We Know:

The exact cause of AL amyloidosis is unknown, but it involves the production of abnormal amyloid proteins by plasma cells. There are no specific risk factors presently identified, but we do know that:

- The average age at diagnosis is 65 years
- It is more common in men than in women
- It is not hereditary

Diagnosing Amyloidosis

Many symptoms of amyloidosis are vague. Your health care provider may perform several tests to confirm amyloidosis and which organs are involved.
These tests may include:

- Physical exam
- Detailed medical history
- Blood tests
- Urine tests
- Echocardiogram (Echo)
- MRI
- CT Scan
- Biomarker test
- Biopsy - to confirm amyloid deposits

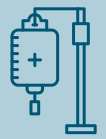
Treatment of Amyloidosis

You should work with your doctor to determine the best course of treatment based on the severity of your AL amyloidosis and which organs have been affected.

Chemotherapy - is the primary treatment aimed at preventing the growth of the cells that produce amyloids. It can be administered orally or by intravenously.

Immunotherapy - involves treatment with antibodies that target the cells that produce amyloids.

Chemotherapy plus bone marrow (stem cell) transplant - this has a more significant and lasting effect compared to chemotherapy alone, but it is suitable for only about 20% of AL amyloidosis patients because of the high risk, especially for those with heart problems.



Managing amyloidosis involves a comprehensive approach to your health.

Some ways to maintain your overall well-being:

- Manage appetite changes
- Prioritize rest and recovery
- Boost your mood with exercise
- Stay connected to support

Medications can slow or stop the amyloids forming but does not remove them. Once the amyloids are no longer being made, your immune system can help remove them. Research is currently being done to develop special antibodies that may remove amyloids deposits.