

Understanding AL Amyloidosis

What is AL amyloidosis?

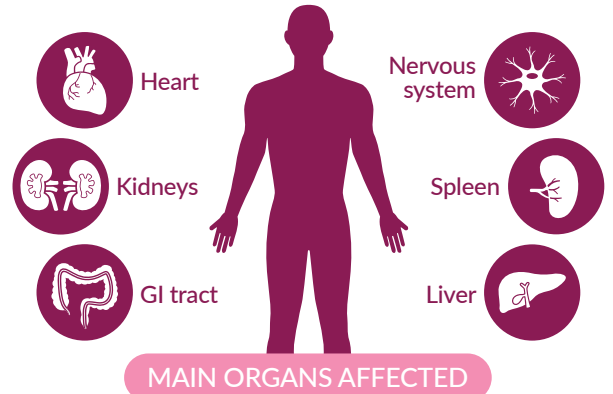
A rare disorder in which abnormal plasma cells grow in the bone marrow. Normal plasma cells are a type of white blood cell that produces antibodies. The abnormal plasma cells in AL amyloidosis make misformed antibody light chain proteins



The misformed light chains clump together to form amyloid fibrils



Amyloid fibrils deposit in the body's organs, leading to organ failure



AMYLOIDOSIS LIGHT CHAIN COMMON SYMPTOMS*

FOAMY URINE



FATIGUE



SWELLING
IN LEGS
AND
ANKLES



SHORTNESS
OF BREATH



UNEXPLAINED
WEIGHT LOSS



NUMBNESS
AND TINGLING
IN HANDS
AND FEET



When the heart is severely affected by AL amyloidosis, it can be life-threatening. An early and accurate diagnosis is important.

*Symptoms are unique to each patient and depend on which organ is affected.

How is AL amyloidosis diagnosed?



History and physical examination



Blood and urine tests



Special Congo red staining on a tissue biopsy (bone marrow, abdominal fat pad, or other organ)



Cardiac imaging such as an echocardiogram or an MRI



- General practitioners, hematologists, cardiologists, nephrologists, and neurologists should recognize the symptoms of AL amyloidosis
- Some symptoms are nonspecific, meaning that they could be caused by several diseases. For this reason, it often takes several doctor visits before a diagnosis of AL amyloidosis is made
- Once a doctor diagnoses someone with amyloidosis, he or she must make sure it is AL amyloidosis and not some other type

How is AL amyloidosis treated?

Care is coordinated with clinicians that specialize in managing AL amyloidosis. The members of a patient's care team are determined based on the organs affected.

The current standard of care is therapy that targets the plasma cells that produce the misformed light chains.

Current treatments are adapted from treatments used for patients with multiple myeloma.

The most common treatment is Darzalex, Velcade, Cytoxan, and dexamethasone. All four are given for 6 months; after six months, patients continue on Darzalex alone.

New drugs that target the misformed light chains rather than the plasma cells are being studied. Targeting the light chains may help organ function recover faster than plasma cell-directed therapy alone.

AL amyloidosis patients should also consider participating in a clinical trial when possible.

AL amyloidosis and multiple myeloma



Both diseases are considered plasma cell disorders, and sometimes they can occur together.



AL amyloidosis occurs in **10% to 15%** of multiple myeloma patients.



Stem cell transplant can be part of therapy, though far fewer AL amyloidosis patients are candidates compared to multiple myeloma.

What is the difference between multiple myeloma and AL amyloidosis?

FEATURE	MULTIPLE MYELOMA	AL AMYLOIDOSIS
Detectable protein	Abnormal antibodies (called M protein) and incomplete parts of antibodies (light chains)	Incomplete parts of antibodies (light chains), which misform and turn into protein deposits in organs
Organs affected	Mainly kidneys and bones	Mainly heart and kidneys but also the liver, nerves, or other organs
Testing	Bone marrow biopsy that shows a high level of plasma cells (at least 10% but sometimes much higher)	Biopsy of abdominal fat or affected tissue that shows positive for Congo red staining



The MMRF Patient Navigation Center

is a space for patients to connect with patient navigators—who are oncology professionals—for guidance, information, and support.

You can reach the MMRF Patient Navigation Center by phone at **1-888-841-6673**, Monday through Friday from 9:00 AM to 7:00 PM Eastern Time, or on the Web at themmrf.org/support/patient-navigation-center

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