What are examples of systemic amyloidosis?

Light chain (AL) amyloidosis. It's also called light chain or primary amyloidosis. Light chain is a kind of protein. AL is caused by abnormal plasma cells in the bone marrow that make a light chain protein.

Hereditary amyloidosis. This type is linked to genes that are inherited (passed from parents to their children). There are many kinds of hereditary amyloidoses. The most common one is caused by an inherited change (mutation or variant) in the gene of a protein called transthyretin.

Wild-type transthyretin amyloidosis. This type is often a late onset disease linked to aging, and is also known as senile systemic amyloidosis. It's caused by normal (non-mutated or wild type) transthyretin proteins. It's not inherited (passed from parents to their children).

AA (or secondary) amyloidosis. This type is caused by higher levels of serum amyloid A protein. It can happen when there is inflammation or infection that lasted for several months.

What are the symptoms of systemic amyloidosis?

Symptoms of systemic amyloidosis include:

- Weakness or fatigue (feeling very tired).
- Weight loss.
- Heart problems, such as congestive heart failure (heart damage) or a heart beat that is not regular.
- Breathing problems (shortness of breath).
- Swelling of feet or legs because of fluids.
- Stomach pain on your right side.
- Abdominal (belly) swelling.
- Feeling full right after you eat.
- Gastrointestinal (stomach and intestines) bleeding.
- Chest pains.
- Feeling lightheaded (faint or dizzy) when you move suddenly.
- Peripheral neuropathy (peh-RIH-feh-rul noor-AH-puh-thee). This is numbness, tingling, or pain in your hands and feet.

Light chain (AL) amyloidosis or primary amyloidosis

The most common kind of systemic amyloidosis is AL amyloidosis, also called light chain amyloidosis or primary amyloidosis.

AL amyloidosis is the most common disease related to amyloids. Light chain is a kind of protein. Light chain amyloids can build up in:

- Your organs, such as the kidney, heart, or liver.
- Your nervous system tissue.

Other amyloids also can build up in tissues. No matter what caused the amyloids, over time they can make your organs stop working.

MSK doctors are experienced at diagnosing all types of amyloidosis. They can treat the condition causing the amyloidosis, limiting how many amyloids are made.

What is AL amyloidosis?

AL amyloidosis happens when abnormal plasma cells mutate (change) and make too many light chain proteins. These are also called immunoglobulin proteins. They form clumps of proteins called amyloids.

These abnormal proteins can build up in different organs, affecting how they work.

How common is AL amyloidosis?

AL amyloidosis is rare. About 3,000 people in the United States are diagnosed with AL amyloidosis each year.

But many more people may have the disease. Primary care doctors may miss the signs of AL amyloidosis. Some of its symptoms are common in other conditions. It also develops slowly, affecting more organs as time passes.

Diagnosing AL amyloidosis

It's important to get a diagnosis from experts in blood disorders who are familiar with the signs and symptoms of AL amyloidosis. MSK doctors have the experience to make a correct diagnosis with the following tests:

Blood and urine tests: These look for any abnormal immunoglobulin light-chain proteins.

Imaging tests: These check for damage to your heart and other organs that can be affected. You may have an MRI, ultrasound, nuclear imaging, or other tests.

Learn about the role of imaging in diagnosing cancer .

Biopsy: A biopsy is a procedure to take a sample of tissue or cells. You may have a:

- Bone marrow biopsy. This is a procedure to take a small sample of bone marrow from your bone.
- Organ biopsy. This is a procedure to take a small sample from an organ, such as your heart or kidney.
- Fat pad (abdominal) biopsy. This is a procedure to take a small sample from a body part with many blood vessels, such as abdominal (belly) fat.

Treatment for AL amyloidosis

AL amyloidosis treatments do not cure AL amyloidosis. But they can slow it down or stop it from getting worse.

Treatments target abnormal plasma cells. AL amyloidosis starts when abnormal plasma cells mutate (change). They start to make too many light chain proteins (also called immunoglobulin proteins). They form clumps of proteins called amyloids.

Treatments can stop these abnormal immunoglobulin (light chain) proteins from forming. That stops them from making amyloids. Your organs start to work better, and you feel better.

Treatments for AL amyloidosis are chemotherapy, proteasome inhibitors, and antibody drugs.

Treatments used for multiple myeloma can work well for AL amyloidosis. The dose is different for people with AL amyloidosis, because their organs may be damaged.

Proteasome inhibitors to treat AL amyloidosis

Treatment often combines traditional chemotherapy drugs with proteasome inhibitors (PROH-tee-uh-some in-HIH-bih-ters) and antibody drugs.

Proteasomes are large groups of proteins. They help kill other proteins that are no longer needed. Plasma cells often are very sensitive to proteasome inhibitors. These drugs block the activity of proteasomes.

Antibody drugs to treat AL amyloidosis

Plasma cells are also sensitive to antibody drugs. Antibodies can tag the plasma cells and tell the immune system to get rid of them.

Stem cell transplant to treat AL amyloidosis

We may recommend an autologous stem cell transplant to treat AL amyloidosis. A stem cell transplant is also called a bone marrow transplant.

First, we isolate and freeze your own blood-forming stem cells.

Next, before your stem cell transplant, you will have high-dose chemotherapy to kill plasma cells.

Then, we return your stem cells to your bloodstream.

Your MSK care team will test you before chemotherapy. They will make sure your heart, liver, and lungs are healthy enough for the stem cell transplant. If you're not healthy enough, you may have chemotherapy instead.

Organ transplant after AL amyloidosis

AL amyloidosis can cause an organ to stop working well, or to stop working at all. At MSK, we work as a team with specialists in a specific organ, such as the heart, liver, or lungs. If an organ stops working, it may be best to replace it.

You may able to have an organ transplant. We will refer you to a transplant center for specialized care.

New ways to treat AL amyloidosis

MSK is finding new ways to help people with AL amyloidosis. We have had excellent results by adding targeted treatments with certain plasma cells. We also are developing ways to find light chains that form amyloids, even when there are only tiny amounts.

MSK doctors also are doing research studies, known as clinical trials, about new treatments for AL amyloidosis. We're studying antibodies that may be able to remove amyloids from tissues, and other new immune-based therapies.

Learn more about joining our clinical trials for AL amyloidosis .

PREVIOUS
Smoldering Multiple Myeloma

NEXT
Plasmacytoma: Solitary or Extramedullary

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