IOWA HEALTH CARE

What is AL Amyloidosis?

AL amyloidosis is a rare disease where abnormal proteins called **light chains** build up in different parts of the body. These light chains are made by certain cells in the bone marrow. When they clump together, they form something called **amyloid,** which can build up in organs like the heart, kidneys, liver, or nerves. Over time, this buildup can make it hard for these organs to work properly.

Risk Factors

- Being over age 60
- Having a bone marrow disease called multiple myeloma
- Long-term problems with the immune system
- Family history of amyloidosis (though AL type is usually not inherited)
- Male gender (men are more commonly affected)

Symptoms

Symptoms can vary a lot depending on where the amyloid builds up. Common signs include:

- Swelling in the legs or belly (due to fluid buildup)
- Feeling very tired or weak
- Weight loss without trying
- Tingling or numbness in hands or feet
- Shortness of breath
- Irregular heartbeat
- Easy bruising, especially around the eyes
- Problems with urination or foamy urine (a sign of kidney trouble)

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Diagnosis

Doctors usually start by reviewing symptoms, doing a physical exam, and running blood and urine tests. To confirm AL amyloidosis, a small sample of tissue (biopsy) is taken and checked under a microscope. Other tests, like heart or kidney scans, help see how much the organs are affected.

Treatment Options

There is no cure, but treatments can help slow the disease and manage symptoms. Options may include:

- Chemotherapy drugs to stop the cells from making more light chains
- Stem cell transplant in some patients
- Medications to protect the heart, kidneys, and other affected organs
- Diuretics (water pills) to reduce swelling
- Ongoing monitoring and support from a care team

What You Can Do on Your Own

- Eat a balanced, low-salt diet to help manage swelling
- Rest when tired, but try gentle activity to stay strong
- Take medicines exactly as prescribed
- Keep up with medical appointments and lab tests
- Let your doctor know if symptoms get worse

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Frequently Asked Questions

1. Is AL amyloidosis cancer?
 No, but it is related to a bone marrow problem that is similar to cancer. It needs treatment just like cancer does.
2. Can AL amyloidosis be cured?
 It cannot usually be cured, but treatment can slow it down and improve quality of life.
3. Is it inherited?
 No, AL amyloidosis is not passed down in families.
4. How long can someone live with this condition?
 This depends on how early it's found and what organs are affected. Some people live many years with proper care.
5. What organs are most at risk?
 The heart and kidneys are commonly affected, but the disease can also affect the liver, nerves, and digestive system.

When to Seek Additional Help

- Sudden swelling or weight gain
- Chest pain or trouble breathing
- Fainting or dizziness
- Rapid heartbeat
- Less urine than usual or dark-colored urine
- Confusion or new numbness in your body