

Amyloidosis and Heart Failure

A HEARTLIFE PATIENT & CAREGIVER GUIDE



FOR PATIENTS AND CAREGIVERS

Amyloidosis is a rare condition where abnormal proteins, called amyloid, misfold and build up in organs and tissues. When amyloid deposits in the heart, it can lead to serious problems with heart function and heart failure. Early diagnosis is key to improving outcomes.



MAIN TYPES OF AMYLOIDOSIS

01 AL (LIGHT CHAIN) AMYLOIDOSIS

- Caused by abnormal plasma cells producing light chains.
- Can affect the heart, kidneys, nerves, and digestive system.

02 ATTR (TRANSTHYRETIN) AMYLOIDOSIS

- **Wild-Type ATTR:** Not inherited, usually affects older adults and often involves the heart.
- **Hereditary ATTR (ATTRv):** Genetic form passed through families, impacting the heart, nerves, and sometimes digestion.

03 AA (SECONDARY) AMYLOIDOSIS

- Caused by chronic inflammation (e.g., rheumatoid arthritis, chronic infections).
- Mainly affects the kidneys.

OTHER ORGANS AFFECTED

Other organs that may be involved include the liver, nerves, kidneys, and digestive system — but the heart is often one of the most affected organs.



HOW AMYLOIDOSIS RELATES TO HEART FAILURE

When amyloid builds up in the heart muscle, it makes the heart stiff and thick. This is called **restrictive cardiomyopathy**. It becomes harder for the heart to fill with blood and pump it out, leading to heart failure symptoms like fatigue, swelling, and shortness of breath.



SIGNS AND SYMPTOMS

- Shortness of breath (especially during activity or lying flat)
- Swelling in the legs, ankles, or abdomen
- Fatigue and weakness
- Irregular heartbeat or palpitations
- Dizziness or fainting
- Numbness or tingling (especially in hereditary forms)
- Weight loss without trying
- Easy bruising or enlarged tongue (more common in AL amyloidosis)



HOW AMYLOIDOSIS IS DIAGNOSED

- **Blood and Urine Tests:** Check for abnormal proteins and organ function.
- **Imaging Tests:** Echocardiogram, cardiac MRI, or specialized nuclear scans.
- **Tissue Biopsy:** Small sample of fat, bone marrow, or heart tissue analyzed for amyloid deposits.
- **Genetic Testing:** To detect hereditary ATTR mutations.



A combination of tests is often needed for a clear diagnosis.



TYPES OF MEDICATIONS AVAILABLE

- **TTR Protein Stabilizers:** Help prevent misfolding of transthyretin protein in ATTR amyloidosis.
- **Gene Silencers:** Reduce the production of abnormal transthyretin proteins.
- **Chemotherapy or Stem Cell Therapy:** For AL amyloidosis to reduce abnormal plasma cells.
- **Fibril Disrupters (In Trials):** Aim to clear existing amyloid deposits.
- **Supportive Heart Failure Medications:** Especially diuretics to manage fluid buildup.



LIFESTYLE TIPS

- Follow a low-sodium, heart-healthy diet
- Monitor weight daily for sudden changes
- Pace activities and conserve energy
- Track any new or worsening symptoms
- Stay connected to specialized amyloidosis clinics or support networks
- Maintain open communication with your healthcare team

WHY EARLY DETECTION MATTERS

- Helps prevent severe organ damage
- Expands available treatment options
- Improves quality of life and long-term survival
- Provides the best chance for slowing disease progression

KEY QUESTIONS TO ASK YOUR DOCTOR

Could my heart failure symptoms be linked to amyloidosis?

What tests are needed to confirm the diagnosis?

What type of amyloidosis do I have?

What treatment options are best for my type of amyloidosis?

Should I consider genetic testing for myself or my family?

How will my treatment plan be different because of amyloidosis?



Take Action Today!

Advocating for your heart health starts with understanding heart disease and other conditions that affect your cardiovascular system. Learn your numbers, follow your care plan, and work closely with your healthcare team. Small, consistent steps can make a big difference for your long-term heart health.



HEARTLIFE ACADEMY

For more information on Amyloidosis and other support please visit us at heartlife.ca/academy/



HeartLife FOUNDATION

Canada's patient-led heart disease charity
"It's About Life, Not Failure™"



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Our Mission

The HeartLife Foundation is a patient-driven charity whose mission is to transform the quality of life for people living with cardiovascular diseases by engaging, educating, and empowering a global community. We aim to create lasting solutions, drive innovation, and build healthier lives for patients, caregivers, and families worldwide.