

# AMYLOIDOSIS DECODED



Amyloidosis is a rare disease that occurs when abnormal amyloid proteins build up in tissues and organs. Left untreated, this can lead to organ failure and death.

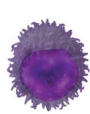
There are several types of amyloidosis, named with an 'A' for amyloid, followed by letter(s) indicating the specific type.\*

## LIGHT CHAIN AMYLOIDOSIS (AL)

AL amyloidosis is a common type of systemic amyloidosis.

### HOW IT HAPPENS:

- 1 Plasma cells produce too many abnormal light chain proteins.



PLASMA CELLS



ABNORMAL LIGHT CHAIN PROTEIN

- 2 The light chains misfold and clump together, creating amyloid fibrils.



ABNORMAL LIGHT CHAIN PROTEIN



AMYLOID FIBRILS

- 3 Amyloid fibrils build up in organs, where they can cause significant and life-threatening damage.



AMYLOID FIBRILS



ORGAN BUILDUP

### MAY AFFECT MULTIPLE ORGANS, INCLUDING:



Heart



Intestine



Kidneys



Soft Tissue



Liver



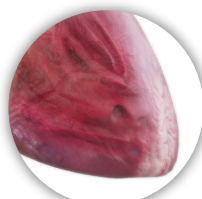
Nerves



Stomach

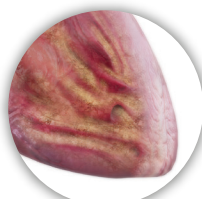
## TRANSTHYRETIN AMYLOIDOSIS (ATTR)

ATTR typically causes a buildup of amyloid fibrils in the heart and/or nerves, making it harder to pump blood through the body.



NORMAL HEART

VS



AMYLOIDOSIS

### AMYLOIDOSIS SYMPTOMS INCLUDE

BRUISED-LOOKING EYES

TONGUE SWELLING

DIFFICULTY SWALLOWING

LOW BLOOD PRESSURE

DIFFICULTY BREATHING

SEVERE FATIGUE

UNINTENTIONAL WEIGHT LOSS

KIDNEY FAILURE

DIARRHEA / CONSTIPATION

PROTEINURIA (FROTHY URINE)

SWELLING OF THE LEGS AND/OR ABDOMEN

CARPAL TUNNEL

### HOW IS AMYLOIDOSIS DIAGNOSED?

Lab tests, biopsy, and imaging tests can detect amyloidosis.

Symptoms can be wide-ranging and subtle, often not presenting until the disease has progressed. Early detection is critical to expedite treatment, reduce organ involvement, and improve outcomes.

NUMBNESS AND TINGLING

## FACTS ABOUT AL AMYLOIDOSIS

AL is an under-recognized disease. Approximately 3,260 people are diagnosed with AL amyloidosis per year in the United States.<sup>1</sup> Patients often experience multiple signs and symptoms for over a year before receiving a diagnosis.



**+75%** of patients have symptoms affecting **2+ organ systems**.<sup>2</sup>

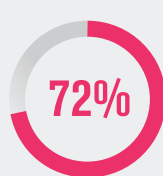


**Two-thirds** of patients see **3 or more providers** before receiving a diagnosis.<sup>1</sup>

### DELAYED DIAGNOSIS

**2.7 years**

Median time from symptom onset to diagnosis.<sup>3</sup>



Up to **72%** of patients experience their first symptom more than a year prior to diagnosis.<sup>4</sup>

## TREATMENT OPTIONS FOR AMYLOIDOSIS

There is no cure for amyloidosis, but varied treatments can effectively manage symptoms. There are multiple FDA-approved therapies available for both AL and ATTR that enhance quality of life, decrease disease burden, and improve survival.

## ASH CLINICAL PRACTICE GUIDELINES CAN HELP YOU NAVIGATE:

Screening tests and diagnostic testing strategies used during initial evaluation and workup

Recommendations for both diagnosis and treatment for AL amyloidosis

Support for patients with "high" clinical suspicion for amyloidosis

LEARN MORE

about amyloidosis and access the guidelines.

\*This infographic mainly addresses light chain amyloidosis; other forms of amyloidosis are not discussed.

### REFERENCES

1. Kumar N, Zhang NJ, Cherepanov D, Romanus D, Hughes M, Faller DV. Global epidemiology of amyloid light-chain amyloidosis. Orphanet J Rare Dis. 2022;17(1):278.
2. Szor RS, Fernandes F, Lino AMM, et al. Systemic amyloidosis journey from diagnosis to outcomes: a twelve-year real-world experience of a single center in a middle-income country. Orphanet Journal of Rare Diseases. 2022;17(1):425.
3. Hester LL, Gifkins DM, Bellew KM, et al. Diagnostic delay and characterization of the clinical prodrome in AL amyloidosis among 1523 US adults diagnosed between 2001 and 2019. Eur J Haematol. 2021; 107: 428-435. <https://doi.org/10.1111/ejh.13679>
4. McCausland KL, White MK, Guthrie SD, et al. Light Chain (AL) Amyloidosis: The Journey to Diagnosis. Patient. 2018;11(2):207-216.

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