

KEY SERVICES



Advocacy

Collaborate with health authorities and policymakers to raise awareness, improve care, and influence health policy nationwide.



Peer Support & Community

Connect patients, carers, and health professionals through conferences, online groups, newsletters, and webinars to foster a strong support network.



Education & Awareness

Raise understanding through webinars, videos, stories, and educational tools. Hosting medical conferences and leading campaigns for World Amyloidosis Day (October 26).



Access to Treatments

Advocate for better access by engaging with PHARMAC, supporting local clinical trials, and sharing updates on new and emerging therapies.



CONTACT US



[Amyloidosis.co.nz](https://amyloidosis.co.nz)



Contact@amyloidosis.co.nz



NZ Amyloidosis Patients Association



[Youtube.com /@NZAPA](https://www.youtube.com/@NZAPA)



New Zealand
AMYLOIDOSIS
Patients Association

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*Support, Education
& Advocacy*

WHAT IS AMYLOIDOSIS

Amyloidosis (am-uh-loy-doh-sis) is a rare disease where a protein called amyloid builds up in the body.

These proteins can collect in places like the heart, kidneys, nerves, or stomach, making it harder for those organs to function.

AMYLOIDOSIS TYPES

There are different kinds of amyloidosis. The most common types include:

- **AL (Light-chain):** From abnormal bone marrow cells; often linked to multiple myeloma.
- **ATTR (Transthyretin):** Caused by misfolded protein; can be hereditary (**hATTR**) or age-related (**wtATTR**).
- **AA (Secondary):** Due to chronic inflammation, like arthritis or long-term infections.

Treatment options will depend on the type of amyloidosis, but options are available. Research and emerging drug therapies are growing every year.

CAUSES

Amyloidosis can occur on its own, result from another condition, or be caused by a gene mutation, though in some cases, the cause is unknown. Researchers are currently investigating the causes of the disease.

COMMON SYMPTOMS

General

- Unusual tiredness or fatigue
- Unexplained weight loss
- Swelling in legs, ankles, or around the eyes

Nerves

- Tingling, numbness, or pain in hands/feet
- Carpal tunnel symptoms

Heart

- Shortness of breath
- Irregular heartbeat or palpitations
- Chest discomfort or light-headedness

Kidneys

- Foamy or reduced urine
- Swelling in legs (edema)

Digestive System

- Nausea, constipation, or diarrhea
- Feeling full quickly

Other Clues

- Enlarged tongue with scalloped edges
- Easy bruising or purple patches around eyes

ABOUT US

The New Zealand Amyloidosis Patients Association (NZAPA) is a nationwide, non-profit organisation founded in 2020 by Jaime and Aubrey Christmas, after Aubrey was diagnosed with amyloidosis.

NZAPA exists to support patients, caregivers and medical professionals across Aotearoa navigating all types of amyloidosis—hereditary ATTR (**hATTR**), AL (light-chain), and wild-type.

We're here to connect you with others, share helpful information, and stand by your side. Through support, education, and community, NZAPA walks with you and champions better care and treatment.

