Amyloidosis Program of Calgary

Cardiac Amyloidosis Clinic
South Health Campus Hospital

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What is Amyloidosis?

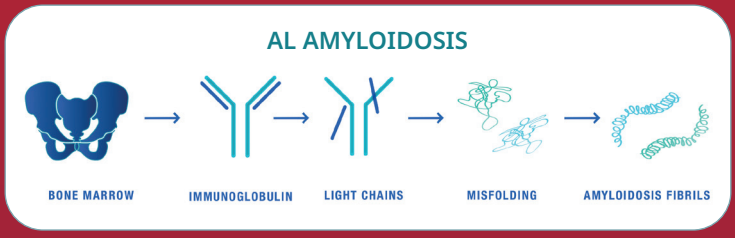
Amyloidosis is a rare, chronic condition in which abnormal proteins bunch together to form amyloid deposits. These deposits can build up in certain body organs such as the heart, nerves and kidneys, and may cause damage.

What is Cardiac Amyloidosis?

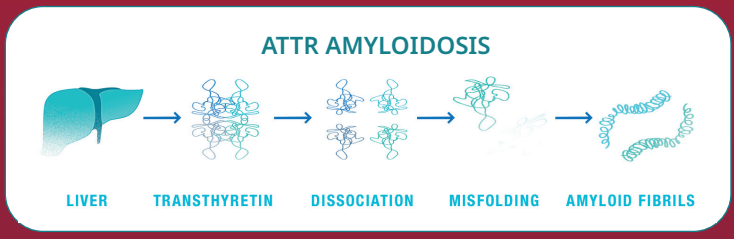
Cardiac amyloidosis is when this disease affects the heart.

There are two main types of cardiac amyloidosis

- Light-chain (AL) - this is a form of cancer that starts in the bone marrow and mostly affects the heart and kidneys.



- Transthyretin amyloidosis (ATTR) (pronounced 'trans-thy-REHtin' 'am-uh-loy-doh-sis') is caused by a liver protein that forms amyloid deposits that mostly affect the heart and nerves. When it affects the heart, it is called ATTR cardiomyopathy (ATTR-CM).



What are the different types of ATTR?

Hereditary ATTR-CM

- This is caused by a change (known as a mutation) in a person's genes.
- This change can be passed down from parent to child and is diagnosed by genetic testing.
- It can affect family members in different ways.

Wild-type ATTR-CM

- This type develops for unknown reasons as people get older.
- It is more common than hereditary ATTR-CM.
- It most often develops in people over 65 years of age.

What are the symptoms of Cardiac Amyloidosis?

Shortness of breath with exertion

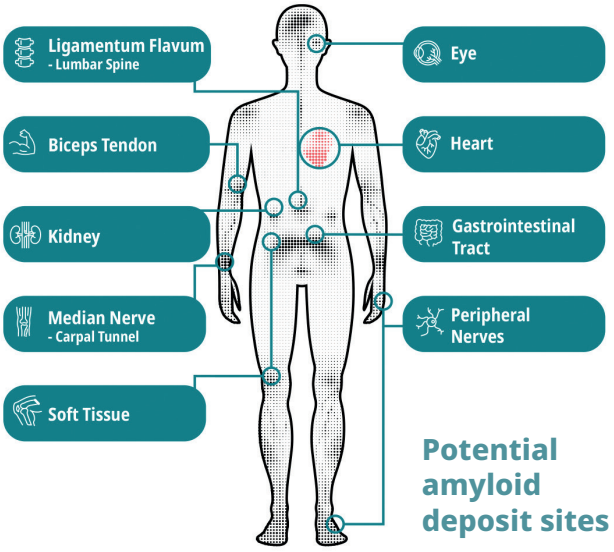
Numbness or tingling of hands

Rapid/ irregular heartbeat

Swelling/ water retention

Non-heart-related symptoms, such as carpal tunnel syndrome, joint, spine, or nerve problems, can develop before heart problems in people with ATTR-CM. Other symptoms can include problems with digestion, bowel or bladder function, vision, hearing, and fatigue.

What are symptoms of Cardiac Amyloidosis? cont'd...



How is Cardiac Amyloidosis diagnosed?

The diagnosis may be suspected because of typical symptoms and the results of routine cardiac tests such as;

Blood work	ECG	ECHO	Cardiac MRI
	Electrocardiogram	Echocardiogram	

Once suspected, other specialized tests are needed to confirm your diagnosis. These will be discussed in further detail with you. Some tests may be ordered before your visit, while others may be ordered after.

PYP Scan
Pyrophosphate

Genetic Testing

How is Cardiac Amyloidosis treated?

Symptoms - symptoms are usually treated with medications that reduce swelling, support blood pressure, control heart rate and reduce stroke risk.

Light chain (AL) - treatment includes chemotherapy and sometimes stem cell transplant. This is prescribed by a hematologist/oncologist.

Transthyretin (ATTR) – treatment includes medications that reduce amyloid protein build-up in the heart and/or nerves. The medication used depends on the type of ATTR (hereditary or wildtype) you have and your symptoms.

Want to know more?

Hereditary/Transthyretin Amyloidosis Canada

The focus of this organization is to help support and advocate for patients and families living with Transthyretin Amyloidosis (ATTR). This group can help connect you and your family with local, regional and national amyloid community supports. Their website is a comprehensive trusted resource for the latest information about the disease state, treatments, clinical trials and advocacy.

https://madhattr.ca/

Or Call: 905-580-2802

Additional Information

Recommended website for cardiac amyloidosis:

Amyloidosis Research Consortium -

https://arci.org/patient-hub/

Do you have questions for your healthcare team?

Take a few minutes to write down your questions for your next visit.

Here are some examples:

What are the effects of amyloidosis on the heart?

What is the prognosis in cardiac amyloidosis?

What is the treatment for cardiac amyloidosis?

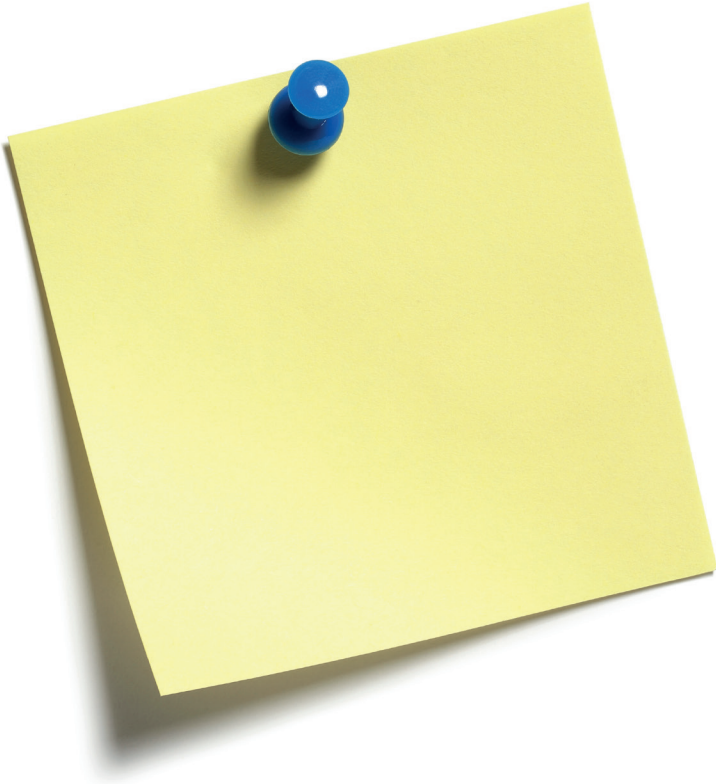
What can I do to take care of myself?

Can I still work?

Where can I get additional information about my disease?

Can I meet other patients with my type of amyloidosis?

Why am I feeling short of breath?



Amyloidosis Program of Calgary

The Amyloidosis Program of Calgary is a group of healthcare providers from different areas who specialize in caring for patients with different types of amyloidosis. Program members and clinics work as a team to ensure patients receive the best possible care. Different clinics may be located at different sites in Calgary.

Our clinic is called the '**Cardiac Amyloidosis Clinic**' and we look after patients with amyloidosis of the heart.

Planning For Your Visit

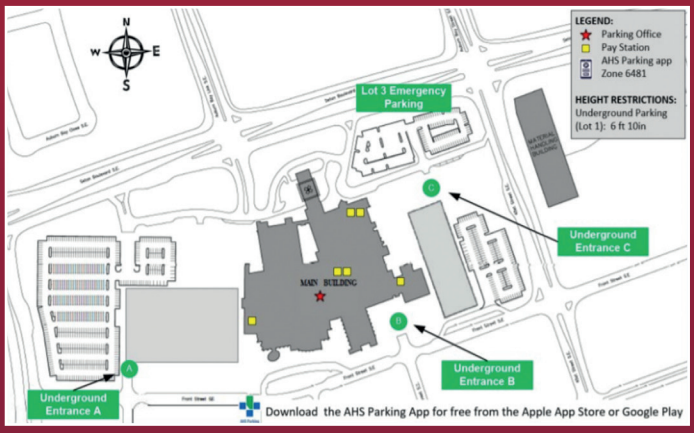
What to bring to your appointment:

Please arrive 15 minutes before your scheduled clinic time and bring the following:

- ☐ Alberta Health Card (or Provincial Health Card)
- ☐ Current medication list
- ☐ Photo ID

Where to Park: South Health Campus - Public Parking

Enter underground parkade - entrance A, B or C. Park in the Green Forest section and proceed to elevator.



Planning For Your Visit cont'd...

Once inside the building and on the main level:

Locate the T1 outpatient elevators and take them up to the 5th floor. Turn left off the elevator area and go down the hall to 5A Cardiology Clinic area and check in at the reception desk.

Once you are checked in:

A registered nurse will take your vital signs and complete a medication history prior to seeing a Cardiologist.

What to expect during your appointment:

Your first visit will take about 60 minutes and a registered nurse will accompany you.

At your visit, your diagnosis and treatment plan will be discussed with you in detail. This may include ordering additional tests or referral to other specialists. Some of your medications may be changed or stopped, while new ones might be added. This will all be explained to you at your visit, but if you have any questions please ask.

Who should attend your appointment:

A lot of information about amyloidosis and its treatment are often discussed at visits. We encourage you to bring a family member or friend to your visits.