

# 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?

NOTES:

# Amyloidosis Programs of Saskatchewan

The Amyloid Programs of Saskatchewan is a team of healthcare providers specializing in cardiac amyloidosis. Team members collaborate to offer optimal care for patients.

**Planning For Your Visit** 

What to bring to your appointment: Arrive 30 minutes before your scheduled clinic time and bring the following with you:

- □ Saskatchewan Health Card
- Current medication list
- Blood work requisition to complete at any lab before your visit, if applicable.

# Checking into the clinic:

Register at the hospital admitting department when you arrive. Once at the clinic, a team member greets you and starts your visit.

What to expect during my appointment: Your first initial visit takes about 90 minutes. During your visit, a nurse checks your vital signs and reviews your medical history. A pharmacist may go over your medications. The cardiologist may adjust your medications and discuss your diagnosis and treatment plan. Additional tests or referrals may be necessary. Feel free to ask any questions.

# Who should attend:

A lot of information about amyloidosis and its treatment is discussed during visits, so it is encouraged you to bring a family member or friend for support.



Regina Cardiac Amyloid Program Heart Function Clinic - Regina General Hospital 1440 14<sup>th</sup> Ave, Regina, SK



**Parking:** Pay-by-Plate parking is available on-site at two locations: 14<sup>th</sup> Ave and 15<sup>th</sup> Ave.

# Saskatoon Cardiac Amyloid Program

Heart Function Clinic - Royal University Hospital 103 Hospital Dr, Saskatoon, SK



**Parking:** Pay-by-Plate parking is available on-site on Levels P3, P4 and P5.



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# Cardiac Amyloidosis Programs

Regina Cardiac Amyloid Program 306-766-4333

Saskatoon Cardiac Amyloid Program 306-655-6684



### What is Amyloidosis?

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

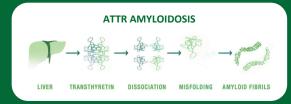
# What is Cardiac Amyloidosis?

**Cardiac amyloidosis** is when this disease affects the heart.

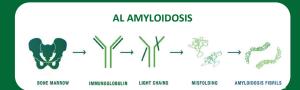
#### There are 2 main types of cardiac amyloidosis

• 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).



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



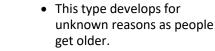
The main medical content of this pamphlet was created by the Amyloidosis Program of Calgary.

# 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



- 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?

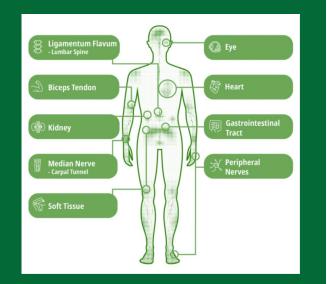
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Shortness of breath with exertion	Numbness or tingling of hands	Rapid/ irregular heartbeat	Swelling/ water retention

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.

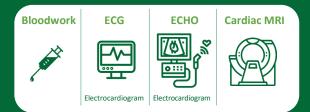
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#### May 2025

# What are the symptoms of Cardiac Amyloidosis? (Continued...)



How is Cardiac Amyloidosis diagnosed? The diagnosis may be suspected because of typical symptoms and the results of routine cardiac tests such as:



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.

**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?

# 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 websites for cardiac amyloidosis: The Canadian Registry for Amyloidosis Research https://amyloidregistry.ca

Message from the Heart http://www.messagefromtheheart.ca/

HeartLife Foundation https://heartlife.ca/