

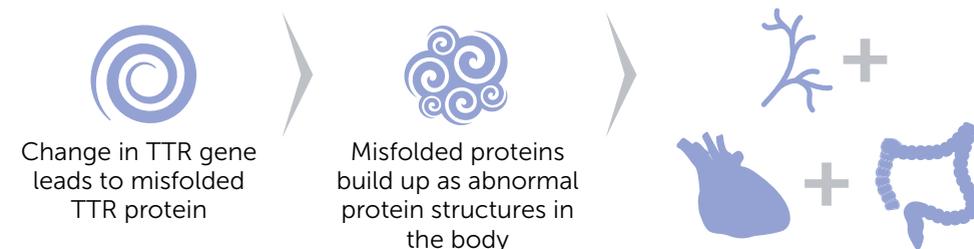
hATTR amyloidosis?

What causes hATTR amyloidosis?

hATTR amyloidosis is a genetic disease caused by a change (mutation) in the gene that makes a protein called transthyretin (TTR), which is primarily made in the liver. These mutations change the shape of TTR proteins – causing them to fold incorrectly and build up as abnormal protein structures (called amyloid fibrils) in various organs in the body.

What does hATTR amyloidosis lead to?

The buildup of amyloid fibrils damage the organs where they are found – especially in the nerves, heart, and digestive system. Because these buildups can occur in almost any part of the body, individuals with hATTR amyloidosis can have a range of symptoms that may seem unrelated.



Resources & Support

For additional information and assistance:

Hereditary Amyloidosis Canada
www.madhattr.ca

The Canadian Amyloidosis Support Network
www.thecasn.org

Canadian Organization for Rare Disorders
www.raredisorders.ca

Orphanet (Canada Page)
<http://www.orpha.net/national/CA-EN/index/homepage/>

Regroupement québécois des maladies orphelines (RQMO)
<https://rqmo.org>



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Hereditary ATTR (hATTR) amyloidosis

A guide for caregivers



Are you a caregiver for someone living with

Familiarizing yourself with hATTR amyloidosis is the first step in your journey to caring for your loved one.

What is hATTR amyloidosis?

Hereditary ATTR (hATTR) amyloidosis is a progressive and rare inherited disease that affects multiple parts of the body, including the nervous system and the heart.



About **50,000 people worldwide** have hATTR amyloidosis



Patients often have to see **5+ doctors** across different specialties **before getting the right diagnosis**



Often takes more than **4 years** from symptom onset **to a diagnosis**

Taking care of yourself (so you can take care of others)

It's important as a caregiver to take care of yourself. It can sometimes feel overwhelming to take care of a person living with hATTR amyloidosis, but neglecting your own well-being can be harmful to you both.

As a caregiver, it's important to focus on your own needs first. If you are drained emotionally and physically, how can you possibly hope to care for another? Here are some tips for taking care of yourself:

Be kind to yourself

This is the new "normal," which is often very difficult to adapt to. It can feel like a rollercoaster ride of emotions with things spiraling out of control. Be assertive and ask for what you need. Most of us don't like to do this, however, it's crucial to staying afloat.

Let others help you

Trying to handle everything by yourself can lead to burnout, mental health and physical health problems. Make sure you have a support system in place to help you through the difficult times.

Talk to others about your feelings

You may think that no one understands, but holding in your feelings will only make you feel isolated and neglected. It's OK to open up and seek out and accept the support of others. Join a group of caregivers so that you are in the company of those who are walking the same path. Often you are able to vent without guilt, as you should when things become overwhelming.

Make time for yourself

It's allowed! Take time off from being a caregiver without feeling guilty. Participate in pleasant, nurturing activities, such as reading a good book or having coffee or lunch with a friend, engage in a hobby, join a club, or take a warm bath. Set boundaries and MAKE time for you to do something YOU love.

Manage your stress

Get proper rest and nutrition. Learn and use stress-reduction techniques, e.g. meditation, prayer, yoga, Tai Chi, whatever practice works best for you.

See your doctor

Are you overeating? Unable to sleep? Always feeling tired? Not keeping up with routine health care appointments? Take these signs seriously. Seeing your doctor, as needed, helps you keep your own health in check.

Stay positive

Change the negative ways in which you view situations. When a negative thought enters your conscious, replace it with a positive one. This does not happen overnight, but when you are able to manage this, it can be so powerful.

Preparing for upcoming appointments

The more you know about hATTR amyloidosis and what to expect, the more prepared and less stressed you will feel. Your loved one's doctor or nurse can be an excellent source of information and can help you look after yourself, as well as provide advice and recommendations to help guide you in your role as a caregiver. Here are some useful tips to help prepare you and your loved one for upcoming doctor's visits:

Call ahead

Prior to an appointment, call to see if the doctor is on schedule. Remind the receptionist of any special needs you may have when you arrive at the office.

Prepare questions ahead of time – make a list

The doctor only has a short visit with the patient. Make sure you let them know what your concerns are in terms of daily care and health. Make a list of important issues to discuss, such as changes in symptoms, medications or general health of your loved one.

Make sure these appointments meet you and your loved one's needs

Ask for the first appointment in the morning or after lunch. The doctor usually has more time then and your wait time is minimal. Clearly convey the reasons for your visit to ensure enough time is allocated.

Take someone with you

A friend or relative can ask questions you feel uncomfortable asking and can help you remember what the physician and nurse said. You may even want to ask them to take notes during the appointment.

Use assertive communication and "I" messages

Ask for what you need, explain what your concerns are, and how the doctor and/or nurse can help. Be specific and very clear by using statements like the following:

- *"I need more information about the diagnosis."*
- *"I will feel better prepared if I know what's in store for my loved one."*
- *"I am feeling overwhelmed/run-down/stressed out. What assistance is available to me so I can provide proper care to my loved one?"*
- *"I need a way for my mother to sleep at night as I am now exhausted being up every two hours with her."*

Enlist the help of a nurse

Nurses are often more accessible and have more time than doctors. Many questions relate more to nursing than to medicine. In particular, a nurse can answer questions about various tests and examinations, preparing for surgical procedures, providing personal care, and managing medications at home.

Learn about genetic testing

It's not always easy to determine whether a disease in a family is passed down from parent to child and genetic tests can help. There is support available. If you are concerned about your genetic status or that of your family members, be sure to discuss this with your doctor.

Visit Hereditary Amyloidosis Canada's website

You will find the latest information on the disease and you can sign up to receive important updates delivered to your inbox. You can also follow us on Facebook and Twitter by clicking on the links on our homepage.