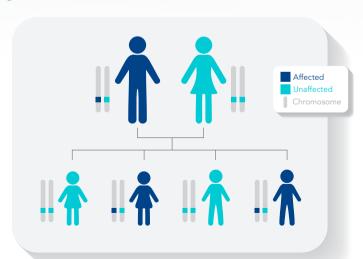


Hereditary ATTR (hATTR) amyloidosis: importance of mapping family health history

This chart can help you map your family's health history and determine who may be at risk for hereditary ATTR (hATTR) amyloidosis.

hATTR amyloidosis—an inherited condition

hATTR amyloidosis is a rare condition that affects an estimated 50,000 patients worldwide. It is an inherited condition caused by a gene change (mutation) that affects the function of a protein called transthyretin (TTR). The age that initial symptoms appear may vary, ranging from the mid-20s to the mid-60s. It is passed down in an autosomal dominant pattern, which means a person only needs to inherit one copy of the affected gene from one parent in order to develop the condition. When one parent carries an autosomal dominant mutation, any child will have a 50% chance of inheriting that mutation.



A family member may inherit the TTR gene with a mutation, but having the mutation does not mean that he or she will develop hATTR amyloidosis. If you have any questions, please contact your healthcare provider.

Working with your family members to complete this worksheet can help educate them about hATTR amyloidosis, its symptoms, and how it is passed down through generations. You can use the other materials in this kit to learn about the cause and symptoms of this condition.

Here is an example of how to fill out each family member's "branch":

Mother Experienced symptoms of hATTR amyloidosis? ✓ Yes □ No	Father Experienced symptoms of hATTR amyloidosis? □ Yes ✓ No
List symptoms: Carpal tunnel, consistent dizziness when standing up leg swelling, chest pain	List symptoms:
Age diagnosed: <u>Not diagnosed</u>	Age diagnosed: Not diagnosed
Other major medical conditions:	Other major medical conditions: Diabetes



Genetic counseling can help you understand your chances of inheriting the condition as well as to become familiar with the testing process and implications of a diagnosis. Talk to your healthcare provider.



The varying symptoms of hATTR amyloidosis

Autonomic Dysfunction

Symptoms of autonomic dysfunction include:

- Urinary tract infections
- Excessive sweating
- Dizziness upon standing
- Sexual dysfunction
- Nausea and vomiting
- Diarrhoea
- Severe constipation
- Unintentional weight loss

Cardiomyopathy

Symptoms of cardiomyopathy include:

- Increasing fatigue
- Dizziness
- Shortness of breath
- Leg swelling (Oedema)
- Palpitations and abnormal heart rhythms (atrial fibrillation)
- Chest pain

Polyneuropathy

Peripheral neuropathy includes symptoms such as:

- Tingling
- Numbness
- Carpal tunnel syndrome
- Burning pain
- Loss of sensitivity to temperature
- Weakness
- Kidney dysfunction

Other Symptoms

- Glaucoma
- Blurred or spotty vision
- Abnormalities of the pupil or blood vessels on the white of the eye
- Detached retina
- Progressive dementia
- Headache
- · Loss of movement control
- Seizures
- Weakness
- Stroke-like episodes



Grandmother Experienced symptoth hATTR amyloidosis? List symptoms: Age diagnosed: Other major medical	hATTR amyloidosi List symptoms: Age diagnosed:	s? □Yes □No	Grandmothe Experienced sym hATTR amyloido List symptoms: Age diagnosed: Other major med	aptoms of sis? □ Yes □ No Experienced syn hATTR amyloide List symptoms: Age diagnosed:	Grandfather Experienced symptoms of hATTR amyloidosis? Yes No List symptoms: Age diagnosed: Other major medical conditions:	
Aunt/Uncle Experienced symptoms of hATTR amyloidosis?	Aunt/Uncle Experienced symptoms of hATTR amyloidosis?	Mother Experienced symptoms of hATTR amyloidosis? ☐ Yes ☐ No List symptoms: Age diagnosed: Other major medical conditions:	Father Experienced symptoms of hATTR amyloidosis? ☐ Yes ☐ No List symptoms: Age diagnosed: Other major medical conditions:	Aunt/Uncle Experienced symptoms of hATTR amyloidosis?	Aunt/Uncle Experienced symptoms of hATTR amyloidosis?	
Keep track of your family's health history Use this space to record any important notes from conversations with your family members, including points about your family's history and follow-up steps.	Sister/Brother Experienced symptoms of hATTR amyloidosis? ☐ Yes ☐ No List symptoms:	Sister/Brother Experienced symptoms of hATTR amyloidosis? □ Yes □ No List symptoms:	You Experienced symptoms of hATTR amyloidosis? ☐ Yes ☐ No List symptoms:	Spouse Experienced symptoms of hATTR amyloidosis? ☐ Yes ☐ No List symptoms:		
Genetic mutation: Notes:	Age diagnosed: Other major medical conditions:	Age diagnosed: Other major medical conditions:	Age diagnosed: Other major medical conditions:	Age diagnosed: Other major medical conditions:		
	Child Experienced symptoms of hATTR amyloidosis? ☐ Yes ☐ No List symptoms:	Child Experienced symptoms of hATTR amyloidosis? □ Yes □ No List symptoms:	Child Experienced symptoms of hATTR amyloidosis? ☐ Yes ☐ No List symptoms:	Child Experienced symptoms of hATTR amyloidosis? ☐ Yes ☐ No List symptoms:	Child Experienced symptoms of hATTR amyloidosis? ☐ Yes ☐ No List symptoms:	
	Age diagnosed: Other major medical conditions:	Age diagnosed: Other major medical conditions:	Age diagnosed: Other major medical conditions:	Age diagnosed: Other major medical conditions:	Age diagnosed: Other major medical conditions:	

Discover information and resources about hATTR amyloidosis at www.hATTRbridge.ca

References:

Hawkins PN. Ann Med. 2015;47(8):625-638.

Hanna M. Curr Heart Fail Rep. 2014;11(1):50-57.

Damy T. J Cardiovasc Transl Res. 2015;8(2):117-127.

Coelho T. Curr Med Res Opin. 2013;29(1):63-76.

National Institutes of Health: Department of Health and Human Services. Genetics Home Reference. Transthyretin amyloidosis. https://ghr.nlm.gov/condition/ transthyretin-amyloidosis. Accessed March 22, 2017.



