

Talking to your doctor about Hereditary ATTR (hATTR) Amyloidosis

If you think you may be experiencing symptoms of hATTR amyloidosis, the first step is to have a discussion with your doctor. Bring this discussion guide to your next GP or specialist appointment – it covers everything you need to have an informed discussion with your doctor about hATTR.

If you haven't already, [complete the risk assessment](#) and bring the results with you to have a record of your symptoms. Having a comprehensive list of your symptoms will help your doctor better understand what you are experiencing.

About hATTR Amyloidosis

hATTR amyloidosis is an inherited, rapidly progressive, and often fatal disease that affects an estimated 50,000 people worldwide. Although anyone can be at risk of hATTR amyloidosis, people of certain ethnicities are at higher risk. Diagnosis can be difficult as symptoms can differ greatly among patients and can affect multiple parts of the body, including the nervous (nerves), cardiovascular (heart), and gastrointestinal (digestive) systems.^{1,2,3}

Some of the most common symptoms of hATTR are listed below but there are many more so it is important to talk to your doctor because if left untreated, the disease can progress quickly.

- Pain and numbness in the feet and hands
- Carpal tunnel syndrome
- Shortness of breath
- Fatigue
- Erectile dysfunction
- Digestive tract symptoms such as diarrhea or constipation

Genetic Testing Confirms a Diagnosis of hATTR

Due to higher incidence of hATTR amyloidosis in certain ethnicities, people of African, Brazilian, French, Haitian, Irish, Japanese, Portuguese, or Swedish descent are considered at-risk.



If you are exhibiting symptoms or are within one of the at-risk populations and recognize a history of these symptoms in your family, ask your doctor about how you can get access to genetic testing. A medical genetic testing company called INVITAE does the testing at no charge and the process is simple. An Amyloidosis specialist listed below can order the genetic testing for you and help determine a possible diagnosis.

Questions for Your Doctor

Asking the right questions can help you get the most out of your appointment. It is suggested that you visit your doctor with this guide and if there is suspicion of hATTR, a referral can be made to a specialist listed below. A specialist can only see you with a referral from your doctor. Consider these suggestions, based on your circumstances, to help guide your conversation with your GP or specialist:

- **I am experiencing symptoms and understand that I am more at risk for hATTR amyloidosis because of my ethnicity - how can I get genetic testing to determine if I carry the hATTR amyloidosis gene?**
- **I am experiencing symptoms of hATTR amyloidosis and would like to be referred to a specialist.**
 - **If concerned about symptoms related to the heart:**
 - Can you provide a referral to a cardiologist?
 - **If concerned about symptoms related to the nervous system (e.g.: brain, eyes, ears, nose, tongue, skin)**
 - Can you provide a referral to a neurologist?

Canadian Specialists and Experts in hATTR Amyloidosis

While hATTR is a rare disease, treatment options are available. If your self-assessment says you may be at risk, it is recommended to reach out to an Amyloidosis specialist who can help determine a possible diagnosis. However, it is important to know that only your doctor can refer you to a specialist, so keep the below information accessible to help with your next steps.

Cardiologists and Neurologists

British Columbia

Dr. Michelle Mezei, Neurologist
Neuromuscular Diseases
Gordon & Leslie Diamond Health Care Centre
2775 Laurel Street
Vancouver, British Columbia, V5Z 1M9
Phone: 604-875-4405

Dr. Calvin Tong, Cardiologist
Surrey Heart Function Clinic
9750 140th Street
Surrey, British Columbia, V3T 0G9
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Dr. Margot Davis, MD MSc FRCPC
Clinical Associate Professor, UBC Cardiology
Director, UBC Division of Cardiology
Gordon & Leslie Diamond Health Care Centre
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Wilma J. Koopman, Nurse Practitioner MScN PhD
Neuromuscular Clinic
London Health Sciences Centre
339 Windermere Road
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Dr. Ryan Davey, Cardiologist MD, FRCPC, FACC
Advance Heart Failure, Transplant,
and Pulmonary Hypertension
London Health Sciences
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Dr. Steven K. Baker, BA, BEd, MSc, MD, FRCPC(C), CSCN (EMG)
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Department of Medicine
Peripheral Neuropathy Clinic
Divisions of Physical Medicine and Neurology
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Centre Universitaire de Santé McGill - CUSM
Programme Amyloïdose
1000 boul Décarie
Montreal, Quebec, H4A 3J1
Phone: 514-934-1934

Centre Hospitalier de l'Université de Montréal - CHUM
Programme Amyloïdose
1000 rue Saint-Denis
Montreal, Quebec, H2X 0C1
Phone: 514-890-8000
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Dr. Alexis Gagnon
Clinique Neuro-Outaouais
209 Rue Gamelin, #200
Gatineau, Quebec, J8Y 1W2
Phone: 819-777-2500

Alberta

Dr. Nowell Fine, Cardiologist
Cardiac Amyloidosis Clinic of Calgary
4448 Front Street SE
Calgary, Alberta, T3M 1M4
Phone: 403-956-3748

Dr. Amer A. Ghavanini, MD PhD FRCPC CSCN(EMG)
Clinical Assistant Professor, University of Toronto
Division Head of Neurology
Trillium Health Partners
100 Queensway West
Mississauga, Ontario, L5B 1B8
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Dr. Kerri Schellenberg, MD FRCPC CSCN(EMG) MMedEd
Associate Professor, Neurology -
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Neuromuscular and EMG Clinic,
ALS Clinic, EMG laboratory
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Dr. Vera Bril, BSc, FRCPC, MD
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University Health Network
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Saskatchewan

Dr. Gary R. Small, Co-Director MB ChB PhD MRCP
Cardiac Amyloid Clinic
University of Ottawa Heart Institute
40 Ruskin Street
Ottawa, Ontario, K1Y 4W7
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Institut de Cardiologie de Montréal
Programme Amyloïdose
5000 rue Bélanger
Montreal, Quebec, H1T 1C8
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Health Sciences Centre
Congestive Heart Failure Clinic
300 Prince Philip Parkway
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New Brunswick
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Find out more information and get support through Hereditary Amyloidosis Canada.

Email: info@madhattr.ca
Phone: 905-580-2802

¹ Mohty D, Damy T, Cosnay P, et al. Cardiac amyloidosis: updates in diagnosis and management. Arch Cardiovasc Dis. 2013;106(10):528-540.
² Hanna M. Novel drugs targeting transthyretin amyloidosis. Curr Heart Fail Rep. 2014;11(1):50- 57.
³ Hawkins PN, Ando Y, Dispenzeri A, Gonzalez-Duarte A, Adams D, Suhr OB. Evolving landscape in the management of transthyretin amyloidosis. Ann Med. 2015;47(8):625-638.

