

# 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.<sup>1,2,3</sup>

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

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## 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.

## 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

### Newfoundland

**Health Sciences Centre  
Congestive Heart Failure Clinic**  
300 Prince Philip Parkway  
St. John's, Newfoundland, A1B 3V6  
Phone: 709-777-6300

**Dr. François Jacques**  
Clinique Neuro-Outaouais  
209 Rue Gamelin, #200  
Gatineau, Quebec, J8Y 1W2  
Phone: 819-777-2500

**Dr. Katie Connolly, MD, FRCPC**  
Assistant Professor of Medicine  
Division of Cardiology, McMaster University  
**Hamilton Health Sciences, Cardiac Amyloid Clinic**  
237 Barton Street East  
Hamilton, Ontario, L8L 2X2  
Phone: 905-577-1414

### Nova Scotia

**Dr. Kim Anderson, Cardiologist**  
QEII – Halifax Infirmary  
1796 Summer Street  
Halifax, Nova Scotia, B3H 3A7  
Phone: 902-473-2700

**Dr. Alexis Gagnon**  
Clinique Neuro-Outaouais  
209 Rue Gamelin, #200  
Gatineau, Quebec, J8Y 1W2  
Phone: 819-777-2500

**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  
Phone: 905-848-7100

### New Brunswick

**Dr. Chadi Darwich, Neurologue**  
Hopital Georges-L.-Dumont  
330 ave Université  
Moncton, New Brunswick, E1C 2Z3  
Phone: 506-862-4000

### Ontario

**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  
Phone: 613-696-7000 ext. 1700

### Alberta

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

### Quebec

**Dr. Bobby Jain, Cardiologue**  
2601 rue William-Tremblay  
Montreal, Quebec, H1Y 0E2  
Phone: 514-807-2333

**Wilma J. Koopman, Nurse Practitioner MScN PhD**  
Neuromuscular Clinic  
London Health Sciences Centre  
339 Windermere Road  
London, Ontario, N6A 5A5  
Phone: 519-663-3041

### 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

**Institut de Cardiologie de  
Montréal Programme Amyloïdose**  
5000 rue Bélanger  
Montreal, Quebec, H1T 1C8  
Phone: 514-376-3330

**Dr. Ryan Davey, Cardiologist MD, FRCPC, FACC**  
Advance Heart Failure, Transplant,  
and Pulmonary Hypertension  
London Health Sciences  
339 Windermere Road  
London, Ontario, N6A 5A5  
Phone: 519-663-3428

**Dr. Calvin Tong, Cardiologist**  
Surrey Heart Function Clinic  
9750 140th Street  
Surrey, British Columbia, V3T 0G9  
Phone: 604-582-4550 ext. 764184

**Centre Universitaire de  
Santé McGill - CUSM  
Programme Amyloïdose**  
1000 boul Décarie  
Montreal, Quebec, H4A 3J1  
Phone: 514-934-1934

**Dr. Steven K. Baker, BA, BEd, MSc, MD, FRCPC(C), CSCN (EMG)**  
Associate Professor, McMaster University  
Department of Medicine  
**Peripheral Neuropathy Clinic**  
Divisions of Physical Medicine and Neurology  
HHAC Chair in Neuromuscular Rehabilitation  
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**Dr. Margot Davis, Cardiologist**  
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**Centre Hospitalier de l'Université  
de Montréal - CHUM  
Programme Amyloïdose**  
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Montreal, Quebec, H2X 0C1  
Phone: 514-890-8000  
Fax: 514-412-7709  
www.amylochum.com

**Find out more information and get support through  
Hereditary Amyloidosis Canada.**

**Email: [info@madhattr.ca](mailto:info@madhattr.ca)**

**Phone: 905-580-2802**

<sup>1</sup> Mohty D, Damy T, Cosnay P, et al. Cardiac amyloidosis: updates in diagnosis and management. Arch Cardiovasc Dis. 2013;106(10):528-540.

<sup>2</sup> Hanna M. Novel drugs targeting transthyretin amyloidosis. Curr Heart Fail Rep. 2014;11(1):50-57.

<sup>3</sup> 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.