

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.

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

Alberta

Dr. Gordon Jewett
South Health Campus
Neuromuscular Clinic
4448 Front St SE, Calgary
T3M 1M4
Phone: 403-956-3454
Fax: 403-956-3492
All referrals must be directed
to Neurology Central Access
and Triage (no direct referrals)

Ontario

Dr. Corey Bacher
Scarborough Neurology Clinic
803 - 100 Consilium Place,
Scarborough, Ontario
M1H3E3
Phone: 416-289-0185
Fax: 416-289-0187

**Steven K. Baker MSc,
MD, FRCP(C)**
Peripheral Neuropathy Clinic
1200 Main St West, Hamilton
(McMaster University
Medical Center)
Tel: 905-521-2100 x76946
Fax: 1-905-521-2656

**Amer A. Ghavanini MD PhD
FRCPC CSCN(EMG)**
Credit Valley Hospital
2200 Eglinton Avenue West,
Mississauga Ontario L5M 2N1
Fax: 905-813-4229

Quebec

**Dr Annie Dionne,
Dr Vincent Piché-Martel**
CHU de Québec-Université Laval
Hôpital Enfant-Jésus
clinique des maladies neuromusculaires
du CHU de Québec
1401 18e rue Québec,
Québec, Canada G1J 1Z4
Téléphone: 418-525-4444 x 66893
Fax 418-649-5525

Dr Geneviève Matte, Neurologist
Amyloidosis Clinic at CHUM
1000 St-Denis, Montreal,
Quebec H2X 0C1
Phone: 514-890-8123
Fax: 514-412-7554

Nova Scotia

Dr. Amanda Fiander, MD, FRCPC
Neuromuscular Neurologist
Maritime Neurology
349 Herring Cove Road, Suite 300,
Halifax, Nova Scotia B3R 1V9
Phone: 902-445-1900
Fax: 902-445-1911

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

Email: info@madhatr.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.