

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

Newfoundland

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

Nova Scotia

QEII Halifax Infirmary Hospital
Cardiomyopathy Clinic
Only referrals from specialists are accepted
1796 Summer Street
Halifax, Nova Scotia
Phone: 902-473-2700
Fax: 902-473-8598

New Brunswick

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

Quebec

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

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

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
Fax: 514-412-7709
www.amylochum.com

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

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

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

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

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. Steven K. Baker, BA, BEd, MSc, MD, FRCPC(C), CSCN (EMG)
Associate Professor, McMaster University
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Peripheral Neuropathy Clinic
Divisions of Physical Medicine and Neurology
HHAC Chair in Neuromuscular Rehabilitation
300 Wellington Street North
Hamilton, Ontario, L8L 8E7
Phone: 905-525-9140 ext. 76946

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

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

Alberta

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

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
Phone: 604-582-4550 ext. 764184

Dr. Margot Davis, Cardiologist
Gordon & Leslie Diamond Health Care Centre
2775 Laurel Street
Vancouver, British Columbia, V5Z 1M9
Phone: 604-875-4405

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.