

Talking with Your Doctor about hATTR Amyloidosis

“ The advice that I would give to a patient that has been recently diagnosed with [hATTR] amyloidosis is to listen to your doctor.” – Len,
Living with hATTR Amyloidosis



Are you experiencing symptoms and suspect hATTR Amyloidosis?

- **If you know you have a family history of hATTR amyloidosis**, make sure to gather your healthcare records to help you talk to your doctor. A family medical history is a record of health information about a person and his or her close relatives. A complete record includes information from three generations of relatives, including children, brothers and sisters, parents, aunts and uncles, nieces and nephews, grandparents, and cousins. Giving your doctor a full record of your family history can help with diagnosis.
 - TIP: Try to think back if deceased family members were affected by one of the symptoms of hATTR amyloidosis, as they may have unknowingly been affected by the condition.
- **Be prepared to provide your doctor with a list of all of your symptoms.** It is important to keep in mind that symptoms often seem unrelated, so be sure to consult the hATTR amyloidosis [symptom checklist](#) to learn more about the signs of hATTR amyloidosis. The more educated you are on the condition, the better you can speak to your symptoms.¹
- **Come prepared with any medical records or tests** performed in the past. The more information your doctor has the easier it will be to decide a course of action.¹
- **If you do not have a known family history of the condition**, but you have noticed some of the symptoms of the condition, talk to your doctor about genetic testing (genetic tests are done by analyzing small samples of blood or saliva and they help determine whether you carry genetic mutations for certain diseases) and ways to manage your current symptoms.²
 - A genetic test will show if you carry the gene change (called a genetic mutation) that causes hATTR amyloidosis.



Are you diagnosed with hATTR Amyloidosis?

- **Educate yourself on hATTR amyloidosis.** It is important to have an in-depth understanding of the condition so you can make informed choices and be aware of the presence of new symptoms.
- **Seek a second opinion.** It is normal to ask for a second opinion when talking about treatment plans, use ARC's [My Amyloidosis Pathfinder](#) tool to help find a specialist that is right for you.³
- **After learning about the different treatment plans and options** for managing symptoms, talk with your doctor about what treatment plan works the best for you, keeping in mind your lifestyle and how the symptoms have impacted your day-to-day life so far.⁴
- **When discussing next steps** after receiving your diagnosis, keep these questions in mind:
 - How will hATTR amyloidosis and the treatment options affect my day-to-day life?
 - What changes should I expect at work?
 - Will I be able to maintain my normal social life?
 - To whom should I disclose my condition?
 - How do I talk to family and friends about my diagnosis?
- **As you begin to navigate ways to cope with your condition**, continue to keep an open dialogue with your healthcare team. Update your doctor on new or worsening symptoms and if treatment has helped you manage your symptoms.
- **As you learn more about hATTR amyloidosis** and you become aware of new developments in research, share your findings with your doctor. There is a growing body of information about hATTR amyloidosis, and doctors and patients alike are constantly learning more about the condition. Talking about new research with your doctor can help to inform your treatment plan and improve management of your symptoms.

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