

Talking with your Doctor about hATTR Amyloidosis



Are you experiencing symptoms and suspect hATTR?

- **If you know you have a family history of hATTR amyloidosis**, make sure to compile your healthcare records to help aid conversation with your doctor. Giving your doctor a comprehensive explanation of your family symptoms and how it has impacted your relatives 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 disease.
- **Be prepared to provide your doctor with an overview** 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 way the disease can manifest. The more educated you are on the disease, the better you can speak to your symptoms.¹
- **Come prepared with any medical records or tests** performed previously. 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 disease**, but you have noticed a combination of the symptoms of the disease, talk to your doctor about genetic testing and ways to manage your current symptoms.²
 - A genetic test will show if you carry the mutation that causes hATTR amyloidosis.



Are you diagnosed with hATTR?

- **Educate yourself on hATTR amyloidosis.** It is important to have an in-depth understanding of the disease so you can make informed decisions and be aware of the presence of new symptoms.
- **Seek a second opinion.** It is normal to ask for a second opinion when discussing 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 in my professional life?
 - Will I be able to maintain my normal social life?
 - To whom should I disclose my disease?
 - How do I talk to family and friends about my diagnosis?
- **As you begin to navigate ways to cope with your disease**, continue to keep an open dialogue with your health care 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 disease. Discussing new research with your doctor can help to inform your treatment plan and improve management of your symptoms.

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