

How to Talk with Your Family about Your hATTR Amyloidosis Diagnosis?

Talking to your family members about your hATTR amyloidosis diagnosis is an important first step in your disease journey. You can help your family members understand your specific symptoms as well as the treatment options available to you. It's also important for them to know that hATTR amyloidosis is passed down through family members (genetically inherited) and that they might be affected by the disease. Planning ahead can help make the conversation easier for you. Find some tips below to help guide your discussion.

The biggest lesson I learned is that you don't have to carry that load [of your diagnosis] by yourself.

– Greg, living with hATTR Amyloidosis



1. Decide who you want to tell, and when. These conversations can be difficult, so it is important to have them when you are ready. There is no one “right” way to talk to your family members. You can:

- Talk to one, trusted family member and ask him or her to have the conversation with others
- Meet with family members individually to discuss diagnosis
- Have a “family meeting” to discuss the diagnosis
- For your “family meeting” consider having a non-family member, therapist or support group member to attend to provide guidance and support
- Ask your healthcare team to be there for the conversation¹

Be sure to start the conversation in a way that is best for you and in an environment that you are comfortable in.



2. Plan ahead. Think of some main points you'd like to talk about with your family members. While you can't predict how the conversation will flow, it is helpful to have an idea of topics you'd like to discuss. These topics can include:

- What is hATTR amyloidosis?
- Symptom development and diagnosis
- Impact on your life and your family members' lives
- Next steps and managing your diagnosis

It may be useful to think back to the questions you first had following your diagnosis. Write these questions down, as your family members will likely have similar questions and concerns.



3. Starting the conversation. Starting the conversation. It is important to have a solid understanding of hATTR amyloidosis, your specific symptoms and the treatment options available to you. Come prepared with materials that will help explain the disease. Make sure you are able to provide a simplified description of the disease and symptoms. You can also bring along any medical test results or documents if you think it will be helpful. **Explore the Change the Course website** to familiarize yourself with the disease and refer to the **disease state infographic**.



- 4. Symptom manifestation.** Use the **symptom checklist** tool to help talk about the many different possible symptoms of hATTR amyloidosis. Be sure to explain how the disease can manifest in almost every part of the body, including the nerves, heart and GI tract. You should also discuss how the symptoms might present themselves. This will help your family members understand the impact the disease can have on daily life.
- 5. Symptom management.** Help your family understand that while there is no cure for the disease right now, there are options available to help you manage your symptoms. Consider bringing a family member with you to a doctor's appointment so that he or she can be there when the doctor is explaining your symptom management options.
- 6. Family members' risk.** While your initial conversation will be about your personal diagnosis, your family members need to understand that they might also be affected by the disease. Consult the **genetic materials** section for more information on the hereditary nature of the disease. It may be difficult for family members to think about the effect the disease may have on them, but be sure to stress the importance of thinking ahead.

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