

What to Expect on Your hATTR Amyloidosis Journey



Family History

Given the hereditary (runs in some families) nature of hATTR amyloidosis¹, you may have first become aware of hATTR amyloidosis through patterns in your family's medical history that offered clues for diagnosis. Watching a family member go through their hATTR amyloidosis journey may have shaped the way you perceive hATTR amyloidosis symptoms and treatment options.



Making a Choice

Having a family member with hATTR amyloidosis means that it is possible you might have a gene change (known as a genetic mutation) for hATTR amyloidosis as well.¹ Knowing this, there are two courses of action to discuss with your healthcare team:

- 1 Get tested right away or
- 2 Choose to wait



Unanswered Questions

For many people with hATTR amyloidosis, getting a correct diagnosis takes time. Trying to find an underlying diagnosis for hATTR amyloidosis can be a long and frustrating experience, especially if you are not aware that the disease runs in your family.



Symptom Development

Even with a family history of hATTR amyloidosis, often times people mistake symptoms as part of the normal aging process and not signs of a more serious health problem. You may find yourself going through temporary periods of good health, but the source of your health issues remains overlooked or continue over time.

Patients often present with a cluster of one, two, three or more red-flag symptoms such as:

- A slight prickling, stinging sensation, or numbness in feet or hands²
- Chronic GI distress (Long lasting stomach upset)³
- Bilateral carpal tunnel (Numbness, tingling, weakness, or pain in on both hands)⁴
- Heart failure⁵



Diagnosis

If you have tingling or numbness in your hands and feet, your doctor might want you to get a biopsy (a procedure to remove a piece of tissue or a sample of cells from your body so that it can be analyzed in a laboratory).

You should also discuss a PYP diagnostic test with your doctor, a procedure involving a scan and blood work performed to confirm or determine if the disease has impacted the heart.⁶

Getting diagnosed early on allows you to have a leg up on managing your hATTR amyloidosis and gives you time to start having the necessary conversations with your doctor and family.



Seeking More Information

Receiving an hATTR amyloidosis diagnosis can be scary, overwhelming and hard to understand. To help you navigate the early days after diagnosis, there are resources to help you make informed choices about your care.⁷



Managing Symptoms

Managing the symptoms of hATTR amyloidosis is an ongoing process because the condition can get worse each day. Your doctor may prescribe medicines to treat the symptoms and the condition's impact on your daily life. However, sometimes you may have to wait for symptoms to become more severe before treatments can start.



Treating the Condition

There are currently no approved treatments specifically for hATTR amyloidosis in the U.S. As TTR proteins are made in the liver, sometimes a liver transplant may be an option to reduce the amount of TTR in the body. It's important to also talk to your doctor about potential treatments or clinical trials (research studies that explore whether a medical strategy, treatment, or device is safe and effective for humans) for hATTR amyloidosis.



Daily Life with hATTR Amyloidosis

Despite medicines that can help manage hATTR amyloidosis symptoms,⁸ your daily life might change as your symptoms progress. You might be faced with hard choices in your personal and professional life.

However, it is vital to stay positive and have hope for the future. There are support groups that can help. You can also:

- Talk with those you trust about your fears and concerns
- Let others know when you need help or support
- Tell others what they can do to be helpful to you



Taking Back Control

Becoming an advocate for what you think are the right choices in regards to treatment and management of hATTR amyloidosis is crucial.⁷ Take the time to learn as much as possible about the condition in order to educate yourself and be able to discuss the condition with your doctors.⁷ Just remember, you aren't alone on your hATTR amyloidosis journey. Building a community of support can help you and your family every step of the way.