hATTR Change the Course
your family, your journey, your life

What to Expect on Your hATTR Amyloidosis Journey

STEP ONE

Family History

Given the hereditary nature of hATTR amyloidosis (hATTR)[1], you may have first become aware of hATTR through your family history. Watching a family member go through their hATTR amyloidosis journey may have shaped the way you perceive hATTR symptoms and treatment options.

STEP TWO

Making a Choice

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

1. **Get tested immediately** or
2. **Choose to wait**

PATIENTS WITHOUT A KNOWN FAMILY HISTORY

Unanswered Questions

Diagnosis is challenging and usually requires seeing several physicians. Those who are not aware of a family history may feel frustrated after undergoing a variety of tests and still await a clear diagnosis of why they have certain symptoms.

STEP THREE

Symptom Development

Even with a family history of hATTR, 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 unaddressed or continue over time.

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

- Tingling/numbness in feet or hands[2]
- Chronic GI distress[3]
- Bilateral carpal tunnel[4]
- Heart failure[5]

STEP FOUR

Diagnosis

If you are suffering from tingling or numbness in your hands and feet, a biopsy may be considered by your healthcare team. If a biopsy confirms amyloid deposits, you should discuss genetic testing for hATTR with your doctor.

You also should discuss with your doctor a PYP diagnostic test, a noninvasive test used when the disease has affected the heart. PYP testing involves a scan and accompanying blood work.[6]

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

STEP FIVE

Seeking More Information

Receiving a hATTR diagnosis can be frightening, overwhelming and hard to understand. To help you navigate the early days after diagnosis, there are resources to empower you to make informed decisions about your care.[7]

STEP SIX

Managing Symptoms

Managing the symptoms of hATTR is an ongoing process due to the progressive nature of the disease. 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.

STEP SEVEN

Treating the Condition

There are currently no approved treatments specifically for hATTR in the U.S. As TTR proteins are made in the liver, sometimes a liver transplant may be appropriate to reduce the amount of TTR in the body. It's important to also talk to your doctor about potential treatments on the horizon or clinical trials for hATTR.

STEP EIGHT

Daily Life with hATTR

Despite medicines that can help manage hATTR symptoms,[8] your daily life might be severely impacted as your symptoms progress. You might be faced with difficult decisions in your personal and professional life. However, it is vital to stay positive and optimistic for your future. There are support and advocacy groups that can provide a sense of community and connect you to others who are sharing the same experiences living with hATTR.

STEP NINE

Taking Back Control

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

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1. Hereditary Amyloidosis: ATTR Amyloidosis. Amyloidosis Foundation, 2018. http://amyloidosis.org/facts/familial/#attr-amyloidosis; 2. Adams D, Coelho T, Obici L, et al. Rapid progression of familial amyloidotic polyneuropathy: a multinational natural history study. Neurology. 2015;85(8):675-682; 3.Gertz MA. Am J Manag Care. 2017;23(7 suppl):S107-S112; 4. Nakagawa M et al. Amyloid 2016; 23(1): 58-63; 5. Coelho T, et al. A physician's guide to transthyretin amyloidosis. Research Gate Amyloidosis; Foundation, 2008. https://www.researchgate.net/publication/265490881_A_Physician's_Guide_to_Transthyretin_Amyloidosis; 6. Hereditary Amyloidosis: Diagnosis. Amyloidosis Foundation, 2018. http://amyloidosis.org/facts/familial/#diagnosis; 7. Information For the Newly Diagnosed: Your First Steps After Receiving an Amyloidosis Diagnosis. Amyloidosis Research Consortium, 2018. http://www.arci.org/newly-diagnosed; 8. Hereditary Amyloidosis: Treatment. Amyloidosis Foundation, 2018. http://amyloidosis.org/facts/familial/#treatment