

Taking Your Next Steps: Life Following hATTR Amyloidosis Diagnosis

Being diagnosed with hATTR amyloidosis can be overwhelming, frightening and hard to process. You may be asking yourself – **where should I go from here?** We have created this guide to help you and your family steer your next steps following diagnosis. It is important to know that you are not alone, and there are resources available to help you through this difficult time. We are here with you every step of the way.



Finding a Support Group

Connecting with other patients can be a great way to cope with your hATTR amyloidosis, since they:¹

- Understand the disease due to their first-hand experience
- Provide tips on finding the right doctor, managing daily activities with hATTR amyloidosis and more

These social interactions can help foster growth and positive change through mutual support.²

hATTR amyloidosis support groups host local meetings for patients and their families. They also provide educational resources, such as:

- Information on finding treatment centers and clinical trials
- Personal and inspirational blogs
- Information about local advocacy or fundraising events

To find a support group close to you, please visit:

Amyloidosis Support Groups

Amyloidosis Research Consortium

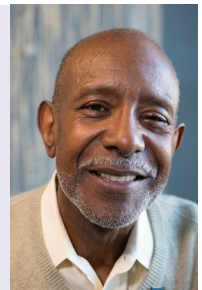
Amyloidosis Foundation

Smart Patients: Amyloidosis Community

To hear from real patients and their experience with support groups, please visit:

Change the Course – Find Support

Live your life to the fullest. If you wait around and not take care of yourself and be positive, as positive as you know how, then you are only doing yourself a disservice. – Len, living with hATTR Amyloidosis





Talking With Your Family

Discussing your diagnosis with your family helps them to better understand what you're going through. You may want to talk with your family about the following:

- The symptoms you are experiencing
- How your diagnosis may affect your family, professional and social life
- How the disease may impact your family
- Your plans for the future

These conversations can be hard so take the time you need to prepare. There is no right or wrong way to go about talking to your family. You could take each family member aside individually, meet as a group, or even ask your doctor to join.⁵

For more helpful tips on how to discuss your diagnosis with your family, refer to:

How to Talk with Your Family About Your hATTR Amyloidosis Diagnosis



Talking With Your Doctor

Throughout your diagnosis, your doctor will be an important resource. Be prepared to update your doctor on how you are feeling, and have a conversation about your next steps and treatment options. You may consider talking about genetic testing for you and your family, due to the hereditary nature of the disease. You can also discuss the possibility of finding a clinical trial for you to participate in. Remember to bring all of your medical records to each doctor's appointment.

For more helpful tips on how to talk to your doctor, refer to:

Talking with your Doctor about hATTR Amyloidosis



Genetic Testing and Counseling

Genetic counseling will allow your family to get tested and know whether they carry a gene associated with hATTR amyloidosis. If they have a mutation, they will be proactive in monitoring and managing the symptoms of hATTR amyloidosis if they do arise.

For more information on genetic testing and genetic counseling, please visit www.hATTRCompass.com.



Finding a Clinical Trial

Clinical trials are designed to research the safety of an investigational drug, medical device or treatment.⁶ These trials are essential for discovering new therapies and getting them approved for wide-spread use. Participating in a clinical trial may allow you to have access to new treatments before they are available.³ Deciding to take part in a clinical trial is a personal decision. It should be an open conversation between you, your doctor and your loved ones.

For more information on clinical trials, please visit:

ClinicalTrials.gov – hATTR Amyloidosis

My Amyloidosis Pathfinder (MAP) Clinical Trial Finder

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