



Change the Course
your family, your journey, your life

Resource Guide



“If you are thinking there might be a genetic cause to the things going on with you like [hereditary ATTR] amyloidosis, I would insist on that being part of the conversation with any medical professional that you have from that point on.”

— Greg,
living with hereditary ATTR amyloidosis

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What is Hereditary ATTR Amyloidosis?

Hereditary ATTR amyloidosis is an inherited condition (passed down through families) that often affects the nerves and heart. Hereditary ATTR amyloidosis is characterized by the deposition of an abnormal protein called amyloid in multiple organs of the body where it should not be, which causes disruption of organ tissue structure and function. In hereditary amyloidosis, amyloid deposits most often occur in tissues of the nervous system, heart and digestive tract.¹



Hereditary ATTR amyloidosis is passed down through family members (genetically inherited). It is an autosomal dominant condition, meaning an individual needs to inherit **only one copy of the mutated gene from one parent** to develop the disease.² If one parent has hereditary ATTR amyloidosis, there is a **50% chance** their child will inherit the mutation.




About **50,000 people worldwide** have hereditary ATTR amyloidosis⁴




Some patients have to see **6+ doctors** across different specialties **before getting the right diagnosis**⁵












It often takes more than **4 years** from symptom onset to a **diagnosis**⁴

The first symptoms of hereditary ATTR amyloidosis typically **appear between the mid-20s and the mid-60s**, involving multiple tissues and organs and often seem unrelated. Because symptoms may be confused with more common conditions, **hereditary ATTR amyloidosis can be hard to diagnose**.⁶




Patients often present with a cluster of two, three or more symptoms, including:


-  **Ocular**
-  **Cardiovascular**
-  **Renal Impairment**¹
-  **Spinal Stenosis**
-  **Carpal Tunnel Syndrome**⁷
-  **Peripheral Sensory-motor Neuropathy**⁸
-  **Chronic GI Distress**¹
GI issues are often caused by nerve damage
-  **Autonomic Neuropathy**⁹
Including Orthostatic Hypotension¹
(Dizziness upon standing)



If you have tingling or numbness in your hands and feet along with other symptoms, **your doctor may 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). If a biopsy confirms amyloid deposits, you should **discuss genetic testing for hereditary ATTR amyloidosis with polyneuropathy** with your doctor.



You should also **discuss a PYP diagnostic test with your doctor**, a procedure involving a scan that is performed to confirm or **determine if the disease has impacted the heart**.¹⁰



Managing the symptoms of hereditary ATTR amyloidosis is an ongoing process because the condition can get worse each day. There are currently approved treatments specifically for hereditary ATTR amyloidosis in the U.S. It is important that you **talk to your doctor** about what treatment options are best for you.

1. Gertz MA. Am J Manag Care. 2017;23(7 suppl):S107-S112; 2. Coelho T, Maurer M, and Suhr O. CMRO. 2013; 29:63-76; 3. Ando Y et al. Orphanet Journal of Rare Diseases 2013; 8:31; 4. Hawkins P et al. Ann Med. 2015;47:625-638; 5. Sikora Kessler, Asia B, Yariias, Aaron & Pollock, Michael & Guthrie, Spencer & Mccausland, Kristen. (2019). Characterizing the Journey to Diagnosis for Patients with Transthyretin Amyloidosis and Accompanying Congestive Heart Failure. Journal of Cardiac Failure. 25. 560. 10.1016/j.cardfail.2019.07.170; 6. Amyloidosis Foundation. Understanding the patient voice in hereditary transthyretin-mediated amyloidosis (ATTR amyloidosis); 7. Nakagawa M et al. Amyloid 2016; 23(1): 58-63; 8. 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; 9. Coelho T, et al. A physician's guide to transthyretin amyloidosis. Research Gate Amyloidosis. Research Gate Amyloidosis, Foundation, 2008. https://www.researchgate.net/publication/263490881_A_Physician's_Guide_to_Transthyretin_Amyloidosis; 10. Hereditary Amyloidosis: Diagnosis. Amyloidosis Foundation, 2018. <http://amyloidosis.org/facts/familial/#diagnosis>



“Because the symptoms for hereditary ATTR amyloidosis can be hard to recognize, it’s important to be aware of them.”

– Len,
living with amyloidosis

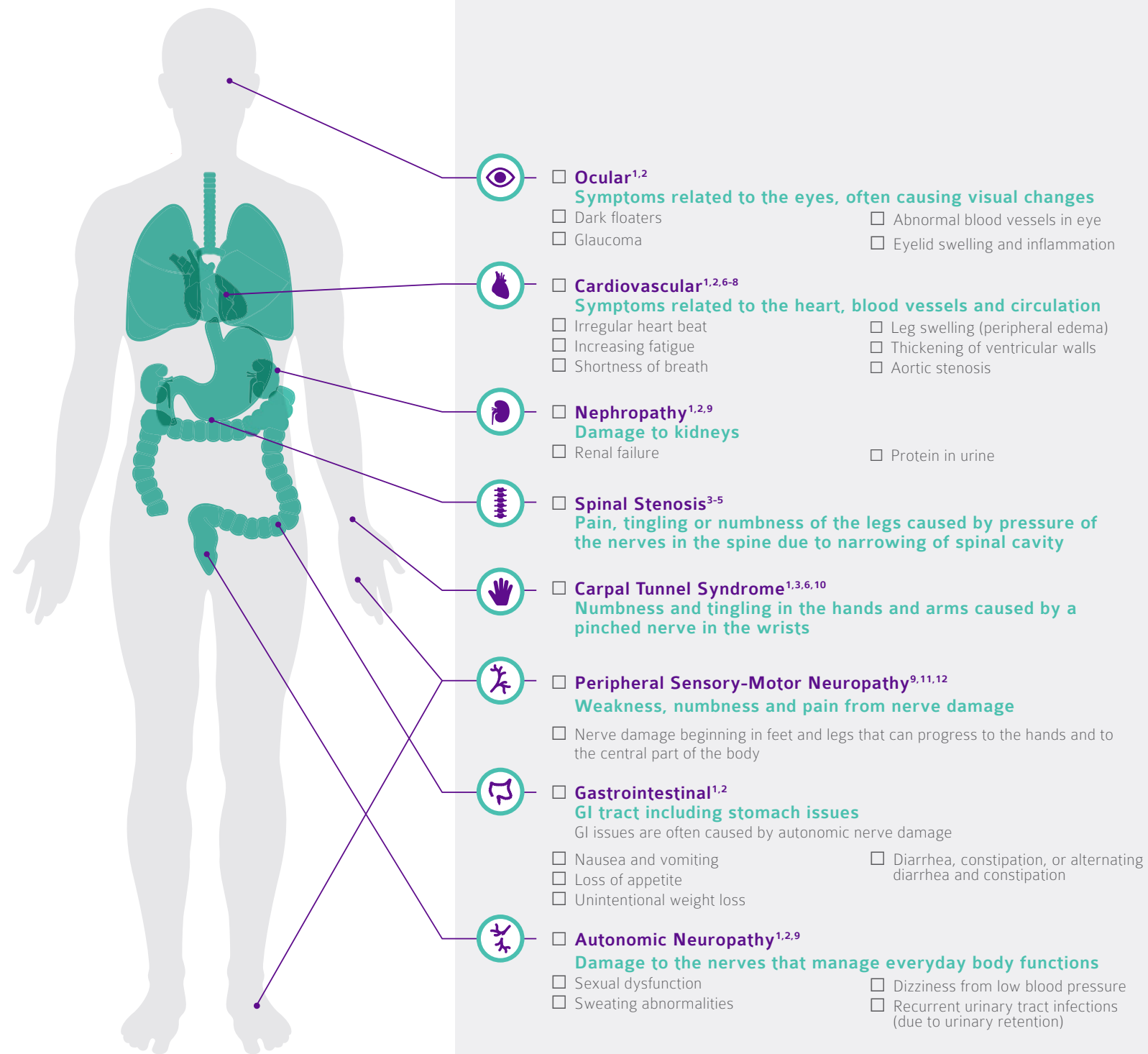
Hereditary ATTR Amyloidosis Symptom Checklist

Hereditary diseases are genetic diseases where a **gene change (sometimes called a gene mutation) is passed down through family members**. It is the inherited (passed down from parent to child) gene mutation that can cause disease.

Hereditary ATTR amyloidosis is an inherited disorder that often affects the nerves and heart. Hereditary ATTR amyloidosis is characterized by the deposition of an abnormal protein called amyloid in multiple organs of the body where it should not be, which causes disruption of organ tissue structure and function. In hereditary ATTR amyloidosis, amyloid deposits most often occur in tissues of the nervous system, heart and digestive tract.

Since hereditary ATTR amyloidosis can appear in many ways and with a broad range of symptoms, it can be hard for doctors and patients to recognize. Patients often have a cluster of two, three or more red-flag symptoms.

Share with your doctor to help find any symptoms of hereditary ATTR amyloidosis you may be experiencing.



1. Gertz MA. Am J Manag Care. 2017;23(7 suppl):S107-S112; 2. 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; 3. Nakagawa M et al. Amyloid 2016; 23(1): 58-63; 4. Cortese A et al. Journal of Neurology, Neurosurgery, and Psychiatry 2017; 88(5): 457-8; 5. Yanagisawa A et al. Modern Pathology 2015; 28(2): 201-7; 6. Donnelly JP, Hanna M. Cleve Clin J Med. 2017;84(12 suppl 3):12-26; 7. Ikram A, et al. J Card Fail. 2017;23(8):S11-S12(P021); 8. Galat A, et al. Eur Heart J. 2016;37(47):3525-31; 9. 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; 10. Lousada I et al. Orphanet Journal of Rare Diseases 2017; 12(Suppl 1): 165 (P7); 11. Ando Y et al. Orphanet Journal of Rare Diseases 2013; 8:31; 2; 12. Conceição et al. Journal of the Peripheral Nervous System. 2016; 21:5-9

What to Expect on Your Hereditary ATTR Amyloidosis Journey



STEP ONE Family History

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



Making a Choice About Genetic Testing

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

1 Get tested right away through **hATTR Compass** (www.hATTRCompass.com), a no-cost, confidential genetic testing and confidential genetic counseling service or

2 Choose to wait



STEP THREE Symptom Development

Even with a family history of hereditary ATTR 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 two, three or more red-flag symptoms such as:

- A slight prickling, stinging sensation, or numbness in feet or hands²
- Chronic GI distress (e.g. long-lasting stomach upset)³
- Carpal tunnel syndrome (e.g. numbness, tingling, weakness or pain in both hands)⁴
- Heart failure⁵



Unanswered Questions

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



STEP FOUR Diagnosis

If you have tingling and numbness in your hands or feet along with other symptoms, 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 that is 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 hereditary ATTR amyloidosis and gives you time to start having the necessary conversations with your doctor and family.



STEP FIVE Seeking More Information

Receiving a hereditary ATTR 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



STEP SEVEN Treating the Condition

There are a number of FDA-approved products that treat different manifestations of hereditary ATTR amyloidosis in the U.S. It is important that you talk to your doctor about what treatment options are best for you. 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.



STEP EIGHT Daily Life with Hereditary ATTR Amyloidosis

Despite medicines that can help manage hereditary ATTR 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



STEP NINE Taking Back Control

Becoming an advocate for what you think are the right choices in regards to treatment and management of hereditary ATTR 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 hereditary ATTR amyloidosis journey. Building a community of support can help you and your family every step of the way.



STEP SIX Managing Symptoms

Managing the symptoms of hereditary ATTR 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.

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>

Talking with Your Doctor about Hereditary ATTR Amyloidosis



Are you experiencing symptoms and suspect hereditary ATTR amyloidosis?

- **If you know you have a family history of hereditary ATTR amyloidosis**, make sure to gather your healthcare records to help you talk to your doctor. A family medical history is a record of health information about a person and his or her close relatives. A complete record includes information from three generations of relatives, including children, brothers and sisters, parents, aunts and uncles, nieces and nephews, grandparents and cousins. Giving your doctor a full record of your family history can help with diagnosis.
 - **TIP:** Try to think back if deceased family members were affected by one of the symptoms of hereditary ATTR amyloidosis, as they may have unknowingly been affected by the condition.
- **Be prepared to provide your doctor with a list of all of your symptoms.** It is important to keep in mind that symptoms often seem unrelated, so be sure to consult the hereditary ATTR amyloidosis **symptom checklist (on page 5)** to learn more about the signs of hereditary ATTR amyloidosis. The more educated you are on the condition, the better you can speak to your symptoms.¹
- **Come prepared with any medical records or tests** performed in the past. 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 condition**, but you have noticed some of the symptoms of the condition, talk to your doctor about genetic testing (genetic tests are done by analyzing small samples of blood or saliva and they help determine whether you carry genetic mutations for certain diseases) and ways to manage your current symptoms.² It is important to understand that not all patients with hereditary ATTR amyloidosis have a known family history.
 - A genetic test will show if you carry the gene change (called a genetic mutation) that causes hereditary ATTR amyloidosis.
- **After talking to your doctor, consider seeking another opinion.** It is reasonable to ask for a second opinion when talking about treatment plans, use ARC's **My Amyloidosis Pathfinder (<https://www.myamyloidosispathfinder.org/>)** tool to help find a specialist that's right for you.³

Listen to [your doctor]. I know my own body, but they know this disease much better than I do. And they know the symptoms, and they know how to treat these symptoms.

— Greg, living with hereditary ATTR amyloidosis



Have you been diagnosed with hereditary ATTR amyloidosis?

- **Educate yourself on hereditary ATTR amyloidosis.** It is important to have an in-depth understanding of the condition so you can make informed choices and be aware of the presence of new symptoms.
- **Consider a second opinion.** It is reasonable to ask for a second opinion when talking about treatment plans, use ARC's **My Amyloidosis Pathfinder (<https://www.myamyloidosispathfinder.org/>)** 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 your next steps** after receiving your diagnosis, keep these questions in mind:
 - How will hereditary ATTR amyloidosis and the treatment options affect my day-to-day life?
 - What changes should I expect at work?
 - Will I be able to maintain my normal social life?
 - To whom should I disclose my condition?
 - How do I talk to family and friends about my diagnosis?
- **As you begin to navigate ways to cope with your condition**, continue to keep an open dialogue with your healthcare team. Update your doctor on new or worsening symptoms and if treatment has helped you manage your symptoms.
- **As you learn more about hereditary ATTR amyloidosis** and you become aware of new developments in research, share your findings with your doctor. There is a growing body of information about hereditary ATTR amyloidosis, and doctors and patients alike are constantly learning more about the condition. Talking about new research with your doctor can help to inform your treatment plan and improve management of your symptoms.

1. Amyloidosis Research Consortium. Newly Diagnosed. "Educate Yourself." <http://www.arci.org/newly-diagnosed/>; 2. National Institutes of Health, Department of Health and Human Services. Genetics Home Reference. "Transthyretin amyloidosis." <https://ghr.nlm.nih.gov/>; 3. My Amyloidosis Pathfinder. "Treatment Centers and Clinical Trials." <https://www.myamyloidosispathfinder.org/>; 4. Amyloidosis Research Consortium. Newly Diagnosed. "Second Opinion." <http://www.arci.org/newly-diagnosed/>

Taking Your Next Steps: Life Following Hereditary ATTR Amyloidosis Diagnosis

Being diagnosed with hereditary ATTR amyloidosis can be overwhelming, frightening and hard to process. You may be asking yourself – where should I go from here? **For more information on being newly diagnosed, check out: (<http://www.arci.org/newly-diagnosed/>)** 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 hereditary ATTR amyloidosis, since they:¹

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

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

Hereditary ATTR 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** (<http://www.amyloidosisupport.org/>)
- **Amyloidosis Research Consortium** (<http://www.arci.org/>)
- **Amyloidosis Foundation** (www.amyloidosis.org)
- **Smart Patients: Amyloidosis Community** (<https://www.smartpatients.com/partners/af>)

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

Change the Course – Find Support (<https://www.hattrchangethecourse.com/hattr-amyloidosis-support-groups/>)

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 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 Hereditary ATTR Amyloidosis Diagnosis (on page 12)



Talking With Your Doctor

Throughout your journey with this disease, 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 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 especially to your initial appointments with your doctor.

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

Talking with your Doctor about Hereditary ATTR Amyloidosis (on page 8)



Genetic Testing and Counseling

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

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



Finding Treatment

There are a number of FDA-approved products that treat different manifestations of hereditary ATTR amyloidosis in the U.S. Deciding which treatment option to take is a personal decision. It should be an open conversation between you, your doctor and your loved ones.

1. Information For the Newly Diagnosed: Your First Steps After Receiving an Amyloidosis Diagnosis. Amyloidosis Research Consortium, 2018. <http://www.arci.org/newly-diagnosed/>; 2. Davison, Kathryn P., James W. Pennebaker, and Sally S. Dickerson. "Who talks? The social psychology of illness support groups." *American Psychologist* 55.2 (2000): 205-3. Gertz MA. *Am J Manag Care*. 2017;23(7 suppl):S 107-S112.; 4. Coping with a diagnosis of chronic illness. American Psychological Association, 2018. <http://www.apa.org/helpcenter/chronic-illness.aspx>; 5. Life-Threatening Illness: What to Tell Family, Friends. WebMD, 2018. https://www.webmd.com/palliative-care/life-threatening_illness_what_to_tell_family_friends#1.

How to Talk with Your Family about Your Hereditary ATTR Amyloidosis Diagnosis?

Talking to your family members about your hereditary ATTR amyloidosis diagnosis is an important 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 hereditary ATTR 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.



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 the 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 hereditary ATTR 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.

“The biggest lesson I learned is that you don't have to carry that load [of your diagnosis] by yourself.”
 – Greg, living with hereditary ATTR amyloidosis



3. Starting the conversation. It is important to have a solid understanding of hereditary ATTR 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 (<https://www.hattrchangethecourse.com/>) or page 2** to familiarize yourself with the disease and refer to the disease state infographic.



4. Symptom manifestation. Use the **symptom checklist (<https://www.hattrchangethecourse.com/symptoms-of-hattr-amyloidosis/>) tool or page 5** to help talk about the many different possible symptoms of hereditary ATTR 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 now approved treatments in the U.S. for hereditary ATTR amyloidosis. 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 treatment options.

1. Life-Threatening Illness: What to Tell Family, Friends. WebMD, 2018. https://www.webmd.com/palliative-care/life-threatening_illness_what_to_tell_family_friends.

Tips for Living Your Best Life with Hereditary ATTR Amyloidosis

After being diagnosed with hereditary ATTR amyloidosis, it is normal to have a wide range of feelings and have questions about how your diagnosis will change your daily routine.

It is important to remember that these are normal feelings and that there is no right or wrong way to feel.¹ While everyone's hereditary ATTR amyloidosis journey is different, it is important to live the life you want to live with hereditary ATTR amyloidosis. **How can you Change the Course?**



Telling Your Family

Talking to your family about your diagnosis is an important step in your hereditary ATTR amyloidosis journey. Be prepared to explain what hereditary ATTR amyloidosis is, your symptoms and possible treatment options.

- Talk to your family 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

Additionally, it is important for family members to understand the hereditary nature of the condition and how they might also have the gene change (known as a genetic mutation)² that causes hereditary ATTR amyloidosis. Finding a support system of friends and loved ones can help to guide your hereditary ATTR amyloidosis journey moving forward.



Talking to Your Friends

Talking with your friends about your hereditary ATTR amyloidosis diagnosis helps to create a support network. Prepare yourself for questions about hereditary ATTR amyloidosis, your treatment plan and experience, and what your friends can do to help.

You may want to consider bringing a family member along who can provide support when you talk with your friends. As you talk with others, you may want to write down questions that come up so that you can discuss them with your healthcare team.



Staying Active

A hereditary ATTR amyloidosis diagnosis does not need to be the end of all physical activity. Many exercises and stretching techniques, such as wall sits, hamstring stretches and balance exercises can actually help manage your hereditary ATTR amyloidosis symptoms.³ It is important to talk to your doctor about his or her recommendations regarding exercise. Exercise can be a great way to interact with others and can still be part of your social life.

There are support groups all over the country and all over the world. From support groups, you can get a great deal of information about the disease.

– Dena, *advocate*



Staying Connected

Staying connected with your friends and community is important in maintaining your social life and relationships. While adjusting to life with hereditary ATTR amyloidosis, keep in mind what you enjoy doing and make it a priority to not lose sight of your connections and what makes you happy.



Connecting with Others with Hereditary ATTR Amyloidosis

Joining a support group can be a great way to meet new friends and talk with others who are going through the same thing. Support groups can help keep you up to date on new treatments and connect you to the right doctors. They can also provide guidance when it comes to finding resources and learning about different ways people cope with hereditary ATTR amyloidosis.⁴ Learn more about support groups available here: www.hattrchangethecourse.com/hattr-amyloidosis-support-groups/



Meeting New People

After your diagnosis, stay open to meeting new people and forming new relationships. It is up to you to decide who needs to know about your condition, and that list of people can change with time.⁵ There is no need to tell strangers upon meeting them, only if it something you wish to share.



Finding Balance

Find balance in everything you do. Keep your treatment plan and healthcare as a top priority, but don't let it consume your entire life. Find time to enjoy yourself, spend time with friends and family and stay connected to your life before diagnosis.⁵

1. Amyloidosis Foundation. Understanding the patient voice in hereditary transthyretin-mediated amyloidosis (ATTR amyloidosis). 2. National Institutes of Health, Department of Health and Human Services. Genetics Home Reference. "Transthyretin amyloidosis." <https://ghr.nlm.nih.gov/condition/transthyretin-amyloidosis>. 3. The Ohio State University Wexner Medical Center. Exercises for Peripheral Neuropathy. <http://www.amyloidosis.org/wp-content/uploads/2017/08/ExercisesPeripheralNeuropathy.pdf>. 4. Amyloidosis Research Consortium. Newly Diagnosed. "Finding Support." <http://www.arcl.org/newly-diagnosed/>. 5. Friedlander, Joan. What to Tell People About Your Rare Disease, Or Not. RARE Daily by Global Genes, 2018. <https://globalgenes.org/raredaily/what-to-tell-people-about-your-rare-disease-or-not/>

Tips for Managing Your Professional Life with Hereditary ATTR Amyloidosis



Define Your Path

Telling your employer about your hereditary ATTR amyloidosis diagnosis is a personal choice. If you decide to tell your employer about your diagnosis, write down what you want to say and review it with loved ones and friends. Practice what you want to say until you feel comfortable. Keeping it simple is key.²

In addition, it might be helpful to make a list of people who need to know about your hereditary ATTR amyloidosis diagnosis. Think about whether you want to let your co-workers know what's going on and how much they need to know. It is your choice who you decide to share this news with and how much information you choose to share.²

One of the things that my wife and I decided to do in regards to amyloidosis and the diagnosis is to do more research on our own.

— Len, *living with amyloidosis*



Know the Facts

When you're getting ready to share your diagnosis with others, it is often helpful to take the time to do some research and learn as much as you can about hereditary ATTR amyloidosis.¹

- Talk with your doctor about symptom management recommendations
- Connect with patient advocacy groups¹



Talk When You Are Ready

If you do decide to tell co-workers, you can start by talking with and getting ideas from someone you trust at work. Some people tell co-workers in a group via a carefully planned email or brief statement in a meeting, so that everyone starts with a basic understanding of what's happening. Perhaps you will want to discuss your diagnosis with your human resources director first and then proceed from there. There is no one right answer for everyone—it depends on your preferences and the culture at your workplace.



Set Expectations

It is important to have an open discussion about how your diagnosis may affect your ability to work. However, just because you've been diagnosed doesn't mean that you have to make major professional changes. Some employers allow changes in job duties and workload, or will allow employees to work from home. Ask your doctor's advice before talking to your employer about making changes at work. Your doctor may be able to write a note explaining what changes are needed.

Talk with your human resources director and supervisor about your needs. Set realistic goals for yourself and be sure that the conversation with your employer is ongoing and updated based on how you're feeling and how the disease is affecting you.³ If you can, try to capture these updates in writing to further protect yourself.



Deal with Stress

Dealing with your hereditary ATTR amyloidosis along with stress from work may be a lot to handle. It's important to be honest with yourself about what you're feeling and take time to care for yourself. It may be helpful to join a support group where you will be able to connect with others going through the same thing.¹ Always remember that you don't have to go through this alone.



1. Information For the Newly Diagnosed: Your First Steps After Receiving an Amyloidosis Diagnosis. Amyloidosis Research Consortium, 2018. <http://www.arci.org/newly-diagnosed/> 2. Friedlander, Joan. What to Tell People About Your Rare Disease. Or Not. RARE Daily by Global Genes, 2018. <https://globalgenes.org/raredaily/what-to-tell-people-about-your-rare-disease-or-not/> 3. The Stigma of Rare Disease: How Do You Tell People About Your Condition? RARE Daily by Global Genes, 2018 <https://globalgenes.org/raredaily/the-stigma-of-rare-disease-how-do-you-tell-people-about-your-condition/>

Continuing with Your Career after Hereditary ATTR Amyloidosis Diagnosis



Talking to Your Boss and Co-workers

It is important to talk to your employer about your diagnosis so that they can know how you're feeling and how it may affect your work. Your manager can only help you if he or she knows about your condition.¹ A few things to consider:

- It may be helpful to make a list of co-workers and clients you think should know about your hereditary ATTR amyloidosis diagnosis.²
- Have a plan going into these conversations and what you would like to get out of them.³
- Discuss how you think your diagnosis will affect your work and how you and your boss can work together to move forward in your career.

For more professional life tips, please visit:

Live Your Life with Hereditary ATTR Amyloidosis (<https://www.hattrchangethecourse.com/living-with-hattr-amyloidosis/>) on page 14



Navigating Human Resources

There are resources available if you need to be out of the office or away from your career due to your hereditary ATTR amyloidosis. You don't have to only rely on your sick and personal days to deal with doctor's appointments or days when you're not feeling well. Through the Family Medical Leave Act (FMLA) and the Americans with Disabilities Act (ADA), you have other options.³

The FMLA allows employees with serious health conditions up to 12 weeks of unpaid, job-protected leave per year.^{3,4} The law is designed to help employees balance their work and family responsibilities. This is a great resource for those with hereditary ATTR amyloidosis and their caregivers. If you're considering taking leave, reach out to your worker's union, if you have one.

The ADA is an equal opportunity law that forbids discrimination against those with disabilities. The law also ensures that people with disabilities have the same opportunities as everyone else.⁵ The ADA defines a disability as "a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment."⁵

Talk to your human resources officer about your rights and what accommodations you can receive.

For more information on the Americans with Disabilities Act and the Family and Medical Leave Act, please visit:

- **Americans with Disabilities Act (<https://www.ada.gov/index.html>)**
- **Family and Medical Leave Act (<https://www.dol.gov/whd/fmla/>)**



Dealing with Disability Discrimination in the Workplace

Disability discrimination is treating someone differently due to their disability or perceived disability.¹ This can include employment-related activities such as:

- Hiring, firing or pay changes
- Employers refusing to provide reasonable accommodation
- Employers asking applicants about their medical history¹

If you are experiencing workplace disability discrimination, talk to your human resources officer. Also, educate yourself on your rights that protect you from this behavior.

If you lost your job because of your disability, you may have a claim against your employer for wrongful termination. You can pursue a wrongful termination case by filing your charge with the Equal Employment Opportunity Commission (EEOC).

For more information on disability rights in the workplace, please visit:

Office of Disability Employment Policy (ODEP) (<https://www.dol.gov/odep/>)



Managing Symptoms at Work

The symptoms of hereditary ATTR amyloidosis may vary from patient to patient and feel different every day. It is important to listen to your body and watch your symptoms to determine how much you will be able to handle at work.³ Find strategies to help you manage your symptoms while in the office. This can include:

- Having regular rest periods throughout the day
- Eating a well-balanced and nutritious diet
- Monitoring your blood pressure and pulse
- Getting up slowly after sitting or lying down⁶

Talk to your doctor about recommendations for your hereditary ATTR amyloidosis symptoms. Remember, there is nothing wrong with taking the time you need for your health.

Glossary of Terms

- **Worker's Compensation:** state-mandated insurance program that provides benefits to employees who suffer job-related injuries and illnesses
- **Family Leave:** unpaid leave of absence for an employee to attend to family concerns
- **Worker's Rights:** fundamental principles and rights at work
- **Wrongful Termination:** an employee being fired illegally

1. Disability Discrimination. Workplace Fairness, 2018. <https://www.workplacefairness.org/disability-discrimination#1>; 2. Friedlander, Joan. What to Tell People About Your Rare Disease, Or Not. RARE Daily by Global Genes, 2018. <https://globalgenes.org/raredaily/what-to-tell-people-about-your-rare-disease-or-not/>; 3. How To Handle A Major Health Issue At Work. Forbes, 2013. <https://www.forbes.com/sites/dailymuse/2013/08/13/how-to-handle-a-major-health-issue-at-work/#4db4b6482ebc>; 4. FMLA Frequently Asked Questions. United States Department of Labor, 2018. <https://www.dol.gov/whd/fmla/fmla-faqs.htm>; 5. Introduction to the ADA. Information and Technical Assistance on the Americans with Disabilities Act, 2018. https://www.ada.gov/ada_intro.htm; 6. Cannon, Jan D., Richard L. Pullen, and Jill D. Rushing. "Managing the patient with amyloidosis." *Dermatology nursing* 16.3 (2004): 225.

Choosing Not to Continue Your Career after Hereditary ATTR Amyloidosis Diagnosis

Deciding to leave your job following your hereditary ATTR amyloidosis diagnosis can be a difficult and personal decision. There is no right or wrong way to go about making this decision, as long as you are doing what's best for you, your family and your health.



Other Work Options

While you may not be able to work and do the same activities as before, there are other options if you don't want to stop working completely. Consider options that allow you to work part-time or work from home. Another option is to find a less time-consuming job that works with your new schedule and lifestyle.¹

For more information about your rights at work and accessing disability, refer to:

Continuing with Your Career After Hereditary ATTR Amyloidosis Diagnosis (on page 18)

After talking with your employer and letting them know you have made the decision to stop working, there are several ways to spend your time valuably.



Get Involved with Advocacy and Support Groups

Getting involved with your local hereditary ATTR amyloidosis advocacy or support group is a great way to stay active after leaving your job. You can choose how much or how little you want to be involved in support groups, which is ideal if you're not sure how your symptoms will progress. Talking with other hereditary ATTR amyloidosis patients and their families is a good way to cope and share your own advice.²

There are many local advocacy and support groups for hereditary ATTR amyloidosis. For more information, please visit:

- **Amyloidosis Support Groups** (<http://www.amyloidosisupport.org/>)
- **Amyloidosis Research Consortium** (<http://www.arci.org/>)
- **Amyloidosis Foundation** (www.amyloidosis.org)
- **Smart Patients: Amyloidosis Community** (<https://www.smartpatients.com/partners/af>)



Volunteer in Your Community

Volunteering can be a great way to stay active and involved without the stress of a full-time job. You'll be giving back to your community and helping others.³ Studies show that volunteering creates better mental and physical health, self-esteem and happiness.³ Like advocacy or support groups, you can choose how much time you want to dedicate to volunteering based on how you're feeling day to day. Consider letting volunteer organizations know about your condition so they can be aware of any limitations and schedule changes that might come up due to your symptoms.

Some suggested volunteer organizations include:

- **American Red Cross** (<http://www.redcross.org/>)
- **Volunteers of America** (<https://www.voa.org/>)
- **Boys & Girls Clubs of America** (<https://www.bgca.org/>)



Prioritize Your Health

It is important to remember that there is nothing wrong with taking time for your health and to recover. Each day may feel different, so you need to listen to your body and do what's best for your mental and physical health. Work and volunteering can cause stress, so it may be more beneficial to let those responsibilities go to focus on yourself.⁴ Your number one priority should always be your mental and physical health.

With [hereditary ATTR] amyloidosis, I had to give up a major portion of [my career] in the outdoor industry. Now, I joined an organization that helps small businesses because, despite my physical limitations, I can still use my brain to stay active in the workplace.

– Greg, living with hereditary ATTR amyloidosis



TIP

For more general information about managing your professional and social life with hereditary ATTR amyloidosis, please visit:

Live Your Life with Hereditary ATTR Amyloidosis

(<https://www.hattrchangethecourse.com/living-with-hattr-amyloidosis/>) or page 14

1. How To Handle A Major Health Issue At Work. Forbes, 2013. <https://www.forbes.com/sites/dailymuse/2013/08/13/how-to-handle-a-major-health-issue-at-work/#4db4b6482ebc> 2. Information For the Newly Diagnosed: Your First Steps After Receiving an Amyloidosis Diagnosis. Amyloidosis Research Consortium, 2018. <http://www.arci.org/newly-diagnosed/> 3. Yeung, Jerf WK, Zhuoni Zhang, and Tae Yeun Kim. "Volunteering and health benefits in general adults: cumulative effects and forms." BMC public health 18.1 (2018): 8. 4. Coping with a diagnosis of chronic illness. American Psychological Association, 2018. <http://www.apa.org/helpcenter/chronic-illness.aspx>

Stress Management

Following Hereditary ATTR Amyloidosis Diagnosis

Living with hereditary ATTR amyloidosis can cause stress and may make it hard to interact with others.¹ It is important to remember that these are normal feelings following diagnosis.² Finding ways to deal with your stress and working through your emotions can help you not feel overwhelmed. Listen to your body and know your limitations, and also listen to your caregiver, as they are there to help.



Be Proactive

After being diagnosed with hereditary ATTR amyloidosis, it's normal to have questions about the condition, treatment and your future. You may consider writing your questions down before visiting your doctor. Preparing these questions will allow you to discuss your fears and concerns so that you'll feel empowered moving forward.²



Talk with Loved Ones

Talking with your family and friends about your hereditary ATTR amyloidosis diagnosis helps to decrease stress. Support from family and friends is important and will allow your loved ones to understand what you're going through and how they can best help you.

If you're not ready to talk openly about your diagnosis with others, another exercise is to write down your thoughts and feelings in a journal. Writing freely about life with the diagnosis can be calming and allow people the opportunity to look at their emotions from a new light.^{3,4} Sharing your journal with your family or a local support group can help to guide you on your hereditary ATTR amyloidosis journey.



Exercise

Being active every day is a great way to reduce stress and manage fatigue. If your doctor agrees, light exercises such as walking, cycling, or yoga are a great option and can be beneficial for your health. While these gentle exercises can be helpful, it's important to listen to your body so that you don't push yourself past your limits.⁵



Take Time for Yourself

Take some time every day to do something that you love, whether it's reading, listening to music, drawing or spending time with your family and friends. You will feel better because you're doing something you enjoy. Creating art can be a great way to improve mood and can help with problem solving.⁶ Remember it is ok to be angry or mad, but try to refocus your energy on a hobby or doing something that you enjoy.



Visit Your Local Support Group

Talking with other hereditary ATTR amyloidosis patients and their families can be a great way to relieve stress and foster hope for the future.⁷ Social support has been shown to have a positive effect on both mental and physical health.^{1,8} Connecting with others offers people an outlet for growth and change through a community.¹ The feeling of giving back to others can be very rewarding and is a great way to get involved in your community.

“

I think support groups are a great way to learn more about the disease and to share your experiences with others.

– Dena, *advocate*

”



For more information on where to find a support group near you, please visit:

- **Amyloidosis Support Groups** (<http://www.amyloidosisupport.org/>)
- **Amyloidosis Research Consortium** (<http://www.arci.org/>)
- **Amyloidosis Foundation** (www.amyloidosis.org)
- **Smart Patients: Amyloidosis Community** (<https://www.smartpatients.com/partners/af>)



Seek Help

If you're feeling overwhelmed and nothing seems to be helping, you should consider seeking professional help. A psychologist can help you work through the emotions that can come along with hereditary ATTR amyloidosis, and can help you accept your diagnosis.²

1. Davison, Kathryn P., James W. Pennebaker, and Sally S. Dickerson. "Who talks? The social psychology of illness support groups." *American Psychologist* 55.2 (2000): 205-2. Coping with a diagnosis of chronic illness. American Psychological Association, 2018. <http://www.apa.org/helpcenter/chronic-illness.aspx>. 3. Spillmann, Rebecca C., et al. "A window into living with an undiagnosed disease: Illness narratives from the Undiagnosed Diseases Network." *Orphanet journal of rare diseases* 12.1 (2017): 71-4. Cain, M. "Therapeutic journaling promotes healing." *Soldiers65* 5 (2010): 12-14. 5. Living Well with AL Amyloidosis: Your Essential Guide. Myeloma UK, 2017. <https://www.myeloma.org.uk/wp-content/uploads/2013/09/Myeloma-UK-Living-Well-with-AL-amyloidosis-Essential-Guide.pdf>. 6. Curi, Krista. "Assessing stress reduction as a function of artistic creation and cognitive focus." *Art Therapy* 25.4 (2008): 164-169. 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. Uchino, Bert N. "Social support and health: a review of physiological processes potentially underlying links to disease outcomes." *Journal of behavioral medicine* 29.4 (2006): 377-387.

Tips on Caring for a Loved One with Hereditary ATTR Amyloidosis

As a caregiver for a loved one with hereditary ATTR amyloidosis, you begin to take on a new role in your relationship. This often requires a major lifestyle change with new responsibilities, and can come along with many adjustments and challenges. Please find some tips below for helping to take care of your loved one.

- Educate Yourself.** Take the time to learn as much as possible about hereditary ATTR amyloidosis and know what to expect for your loved one along the journey. Anticipating your loved one's needs will allow you to feel better prepared when taking care of them.¹ Doctors, patients and caregivers alike are constantly learning more about hereditary ATTR amyloidosis. Staying up to date on research may help you and your loved one(s) make decisions to improve their healthcare management. There are many resources available to the hereditary ATTR amyloidosis community. To learn more about external advocacy and support groups, please visit:
 - **Amyloidosis Support Groups** (<http://www.amyloidosisupport.org/>)
 - **Amyloidosis Research Consortium** (<http://www.arci.org/>)
 - **Amyloidosis Foundation** (www.amyloidosis.org)
 - **Smart Patients: Amyloidosis Community** (<https://www.smartpatients.com/partners/af>)
- Advocate.** An important part of being a caregiver is advocating for your loved one. Learn as much as you can about your loved one's individual diagnosis and particular genetic mutation. By staying informed, you can better serve your loved one by actively participating in conversations with doctors about symptom management and treatment plans.
- Organize Medical Information.** Keeping your loved one's medical information organized and up to date will prepare you to provide your loved one's doctor with symptoms and test results. The more information you are able to provide, the easier it will be for your loved one's healthcare team to determine the right course of action.² Keep an electronic or paper calendar to track all of your loved one's doctor's appointments. Make sure to take notes during doctor's appointments so that you are able to refer back once you get home.
- Discuss.** Talk with your loved one and their healthcare team about what management plan may work best with your lifestyles and your loved one's health. Be sure to keep in mind you and your loved one's lifestyles, and how the symptoms have impacted both of your day-to-day lives so far.³
- Plan Ahead.** Caring for your loved one can be time consuming and can require a lot of your attention. To better manage your time, develop a routine and get yourself onto a schedule. By keeping yourself organized, you are able to prioritize different tasks and ensure you set aside time for yourself.

- Keep Track of Symptoms.** It is important to monitor your loved one's symptoms so you can keep track of their hereditary ATTR amyloidosis progress and discuss with their doctor. If your loved one's symptoms worsen, you'll be able to share a historical record of your loved one's progress with their healthcare team.
- Encourage Independence.** Your loved one may need different levels of care depending on their symptoms and how their condition is progressing. You do not necessarily need to be doing everything for your loved one. Try to find strategies that allow your loved one to be as independent as possible.¹

Taking it day by day makes [hereditary ATTR amyloidosis] manageable. You are doing the best you can for right then and there and tomorrow may be better.

– Brandy, caregiver



- Know Your Limits.** Be realistic about the care you are able to provide and how much of your time you are able to give. Communicate with the healthcare team and other family members—don't be afraid to ask for help.
- Seeking Support.** No one expects you to be able to accomplish everything on your own. Don't be afraid to ask for help from family members, friends and other external resources. Being a caregiver is challenging, so try to keep in mind that your loved one might take things out on you, but that they don't mean it and are just trying to cope and express themselves.
- Taking Care of Yourself.** To provide your loved one with the best care possible, you also need to look out for your own health and well-being. Be sure to make time for your social relationships and keep up with your physical health with regular exercise and healthy eating. **Learn more about self-care tips here:** <https://www.hattrchangethecourse.com/> or on page 26
- Trust Your Instincts.** You know your loved one best. Be sure to have open conversations with your healthcare team about your concerns or questions and don't be afraid to seek a second opinion. Always encourage your loved one to be honest about their symptoms and how they are feeling.
- Take Time to Connect.** While adjusting to this new lifestyle and relationship with your loved one, make it a priority to not lose sight of your relationship prior to diagnosis. Taking the time each day to really connect with your loved one can allow you to relax and enjoy each other's company. This can release hormones that boost mood, reduce stress and trigger biological changes have a positive impact on your physical health—and it can have the same positive results on your loved one.¹

1. Davison, Kathryn P., James W. Pennebaker, and Sally S. Dickerson. "Who talks? The social psychology of illness support groups." *American Psychologist* 55.2 (2000): 205-2. Coping with a diagnosis of chronic illness. American Psychological Association, 2018. <http://www.apa.org/helpcenter/chronic-illness.aspx>. 3. Spillmann, Rebecca C., et al. "A window into living with an undiagnosed disease: Illness narratives from the Undiagnosed Diseases Network." *Orphanet journal of rare diseases* 12.1 (2017): 71-4. Cain, M. "Therapeutic journaling promotes healing." *Soldiers* 65.5 (2010): 12-14. 5. Living Well with AL Amyloidosis: Your Essential Guide. Myeloma UK, 2017. <https://www.myeloma.org.uk/wp-content/uploads/2013/09/Myeloma-UK-Living-Well-with-AL-amyloidosis-Essential-Guide.pdf>. 6. Curi, Krista. "Assessing stress reduction as a function of artistic creation and cognitive focus." *Art Therapy* 25.4 (2008): 164-169. 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. Uchino, Bert N. "Social support and health: a review of physiological processes potentially underlying links to disease outcomes." *Journal of behavioral medicine* 29.4 (2006): 377-387.

Caregiver Tips: Taking Care of Yourself

In some cases, caring for a loved one with hereditary ATTR amyloidosis can become a full-time job, which can result in many changes to your daily life. Taking quality time to care for yourself is an important part of being a caregiver. If you are burnt out or not taking care of your own health, you'll likely struggle to provide the quality care that your loved one needs. Find some tips below on how to care for yourself when serving as a caregiver.



- 1. Keep Up with Your Own Healthcare.** When you are concentrated on the health of your loved one, it is easy to lose sight of your own health. Remember to keep up with your doctor appointments, screenings and medications. Try to incorporate your personal healthcare planning into your caregiver plan, since your health is invaluable and important to your friends, family and community.¹

The advice I'd give to caregivers would be first and foremost if you don't take care of yourself you can't be a good caregiver to your patient.

— Dena, *advocate*



- 2. Understand Your Rights.** Under the Family and Medical Leave Act, most employers are required to provide up to 12 weeks of unpaid, job-protected leave for family members who need to take time off to care for a loved one who is ill. Reach out to your employer to learn more about your rights and start the process for getting leave, if needed.¹



- 3. Stay Social.** Remember to continue to do things you enjoy. Don't be afraid to give yourself a break every once in a while, which helps you to maintain a healthy balance. Finding enjoyment in activities and hobbies can help you to carry on when you face stress and pain in other aspects of your life.² Set time each week to connect with others and do something that brings you joy.¹ The broader your network of support is, the better it is for you. Make time for yourself and to deal with your emotions and what you might be going through.



- 4. Accept Help.** No one is expecting you to do everything on your own—look to friends and family for support. Caregivers need care too! Have a backup plan—if you are sick or get stuck at work, who can you call to come step in and help take care of your loved one? Think of ways that others can help you, and accept the help when offered. Be prepared with a list of potential tasks that others can help with such as grocery shopping, running to the post office, picking up prescriptions or keeping your loved one company while you run an errand. You'll then have a list available when people ask what they can do to help and you have something you can ask of them. Asking for help does not make you any less of a caregiver—it can actually improve your ability to provide quality care.



- 5. Get Individual Help.** As a caregiver, it is normal to feel overwhelmed and need to confide in someone other than family and friends. Speaking with a counselor or social worker can help you sort through your emotions and provide an outside perspective on your situation.³



- 6. Focus on Your Quality of Life.** Your physical, mental and spiritual health all impact your overall quality of life. Make sure to eat right, get enough sleep and carve out time for exercise. These all help to relieve stress and boost your energy, which will have a positive impact on your quality of life and the quality of care you are able to provide.²



- 7. Seek Support.** Joining a caregiver support group is a great way to meet others who are in a similar position as you and are experiencing similar feelings. A support group can provide encouragement and new strategies for coping with and managing problems.¹ **Check out our resource on how to find support here:** <https://www.hattrchangethecourse.com/hattr-amyloidosis-support-groups/>.



- 8. Accept Your Feelings.** Being a caregiver can trigger many different emotions, including fear, guilt, anger and grief. It is important for you to acknowledge and accept your emotions. Keeping your emotions bottled up can have a negative impact on your quality of life and on your loved one's. Find someone you trust to talk to about these feelings—someone who will listen without judgment or interruption. Understand that just because you may be experiencing these emotions does not mean you care for your loved one any less—these emotions are part of being human.



- 9. Take Time to Connect.** Remember what your relationship with your loved one was like before diagnosis and what you valued in the relationship. It is important to not lose sight of this as you adjust to being a caregiver. Dedicate time to connect with your loved one and enjoy each other's company. This can release hormones that boost mood, reduce stress and trigger biological changes, which will have a positive impact on both you and your loved one's physical health.²



- 10. Give Yourself Credit.** At the end of every day, remember that you are doing an amazing, selfless act for your loved one and know how grateful they are for your help. Give yourself credit for all your hard work and find ways to reward yourself for all that you do.

For more resources for caregivers of loved ones with hereditary ATTR amyloidosis, please visit:

- **Amyloidosis Support Group** (<http://amyloidosisupport.org/resources.html>)

- **Amyloidosis Research Consortium** (<http://arc.devbrandcast.com/patients-and-caregivers/>)

1. Caregiver stress: Tips for taking care of yourself. Mayo Clinic. 2018. <https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/caregiver-stress/art-20044784>; 2. Family Caregiving: Finding Caregiver Support and Making Family Caregiving More Rewarding. HelpGuide.org. 2018. <https://www.helpguide.org/articles/parenting-family/family-caregiving.htm>; 3. Caring Advice for Caregivers: How Can You Help Yourself? CancerCare. 2018. https://www.cancerca.org/publications/47-caring_advice_for_caregivers_how_can_you_help_yourself



“ The one thing that I have learned about being a patient is that you have to be your own best advocate. Sort out the negatives and think positive about what is going to happen. ”

– Len,
living with amyloidosis



“ Most of my life, I’ve been a very positive person. And I think it’s that kind of attitude that nothing is going to stop me. I’m going to fight this thing to the bitter end. ”

– Greg,
living with hereditary ATTR amyloidosis

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