

Tips on Caring for a Loved One with hATTR Amyloidosis

As a caregiver for a loved one with hATTR amyloidosis, you begin to take on 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.



1. Educate Yourself. Take the time to learn as much as possible about hATTR 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 hATTR amyloidosis. Staying up to date on research may help you and your loved ones make decisions to improve their healthcare management. There are many resources available to the hATTR amyloidosis community. To learn more about external advocacy and support groups, please visit:

- [Amyloidosis Support Groups](#)
- [Amyloidosis Research Consortium](#)
- [Amyloidosis Foundation](#)
- [Smart Patients: Amyloidosis Community](#)



2. 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.



3. 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.



4. 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 your and your loved one's lifestyles, and how the symptoms have impacted both of your day-to-day lives so far.³



5. 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.



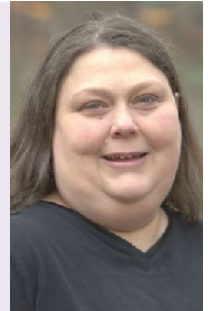
6. Keep Track of Symptoms. It is important to monitor your loved one's symptoms so you can keep track of their hATTR amyloidosis progress and discuss with their doctor. If their symptoms worsen, you'll be able to share a historical record of your loved one's progress with their healthcare team.



7. 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 [hATTR amyloidosis] manageable. You are doing the best you can for right then and there and tomorrow may be better.

– Brandy, caregiver



8. 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.



9. 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.



10. 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](#).



11. 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.



12. 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