

## Caregiver Tips: Taking Care of Yourself

In some cases, caring for a loved one with hATTR 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.<sup>1</sup>

**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 insurance company to learn more about your rights and start the process for getting leave, if needed.<sup>1</sup>



- 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.<sup>2</sup> Set time each week to connect with others and do something that brings you joy.<sup>1</sup> 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.<sup>3</sup>



**6. Focus On Your Quality Of Life.** Your physical, mental, and spiritual health all impacts 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.<sup>2</sup>



**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.<sup>1</sup> 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 your loved ones. Find someone you trust to talk to about these feelings – someone who will listen without judgement 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.<sup>2</sup>



**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 hATTR amyloidosis, please visit:**

**Amyloidosis Support Group**

**Amyloidosis Research Consortium**

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