

# Tips for Living Your Best Life with hATTR Amyloidosis

After being diagnosed with hATTR 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.<sup>1</sup> While everyone's hATTR amyloidosis journey is different, it is important to live the life you want to live with hATTR amyloidosis. **How can you Change the Course?**



## Telling Your Family

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

- Talk with 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)<sup>2</sup> that causes hATTR amyloidosis. Finding a support system of friends and loved ones can help to guide your hATTR amyloidosis journey moving forward.



## Talking to Your Friends

Talking with your friends about your hATTR amyloidosis diagnosis helps to create a support network. Prepare yourself for questions about hATTR 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 cancer healthcare team.



## Staying Active

An hATTR 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 the side effects of hATTR amyloidosis symptoms.<sup>3</sup> It is important to talk to your doctor about any possible physical limitations of the condition, but still find time for the activities you enjoy. Exercise can be a great way to interact with others and can still be part of your social life.



## Staying Connected

Staying connected with your friends and community is important in maintaining your social life and relationships. While adjusting to life with hATTR 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 hATTR 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 hATTR amyloidosis.<sup>4</sup> Learn more about support groups available here: [www.hattrchangethecourse.com/hattr-amyloidosis-support-groups/](http://www.hattrchangethecourse.com/hattr-amyloidosis-support-groups/)

“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*



#### Meeting New People

After your diagnosis, keep yourself 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.<sup>5</sup> 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.<sup>5</sup>