

# Coping With a Diagnosis of ATTR-CM

## Finding support with a rare disease

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Certain signs and symptoms of transthyretin amyloid cardiomyopathy (ATTR-CM) are similar to more common conditions that cause heart failure. People with ATTR-CM may see several different physicians before finally receiving the correct diagnosis.<sup>1</sup> Coping with the challenges of a rare condition may be more manageable with the support of family, friends, and the ATTR-CM community.

### Family and Friends as Caregivers

People who live with ATTR-CM are not all the same: every person, and their family, will have different needs. Creating a support system will be important to ensure that everyone has their individual needs met. Family members may be the first to assist with their loved one's daily needs. In addition, there may be a larger role for a trusted friend or family member to serve as an advocate at doctors' visits.

### Conversations With Trusted Advocates

Discussing a rare condition diagnosis is challenging, and can be even more so when it affects the activities of daily life, the way ATTR-CM can. Friends, family, and colleagues may have difficulty understanding a patient's "new normal." It may be unsettling to learn that a loved one lives with a serious condition, but these conversations are productive in creating a support network that can step in to help. People with ATTR-CM can initiate these conversations when the time is right, or ask a trusted advocate to help explain the condition to others.

### Setting Healthy Boundaries

Understanding the limits that ATTR-CM places on a patient can be a challenging aspect of living with the condition. The diagnosis can be a relief, but discovering how ATTR-CM will affect one's life and its effect on independence takes time to process. A cardiologist and other health care team members may help in educating on the condition. Working with a mental health professional for both patients and caregivers can help in setting boundaries and finding a balance between offering help and accepting it.

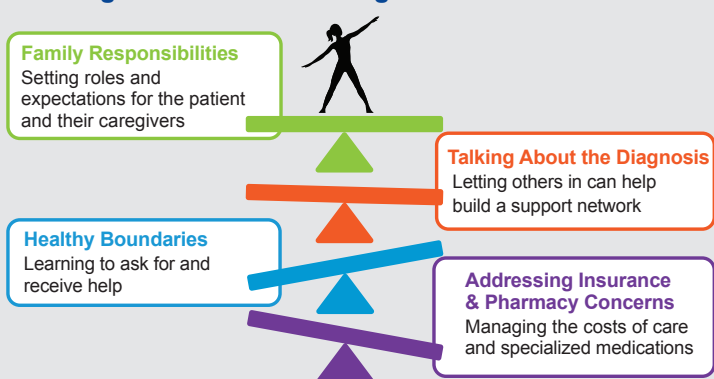
### Specialized Care for a Rare Condition

People with ATTR-CM and their caregivers may take on many new roles, including liaising with a specialty pharmacy. A specialty pharmacy manages treatments for conditions that require special handling, such as refrigeration. Because the process is more involved than going to a local pharmacy, there can be a learning curve. In many cases, physicians will have a point person who can help in working with a specialty pharmacy. Drug manufacturers may also assist by offering support and guidance in obtaining specialty medications.

### The Readjustments of Rare Disease

A diagnosis of ATTR-CM can change many aspects of a person's life. It may affect their family and others around them. Plans may need to be flexible and adjusted often. A responsive support network will go a long way towards being able to pivot more easily to adjust to changing needs. Relationships with family, friends, and colleagues and in the ATTR-CM community can help in creating the right balance.

### Creating Balance While Living With ATTR-CM



**Reference:** 1. Rintell D, Heath D, Braga Mendendez F, et al. Patient and family experience with transthyretin amyloid cardiomyopathy (ATTR-CM) and polyneuropathy (ATTR-PN) amyloidosis: results of two focus groups. *Orphanet J Rare Dis.* 2021;16(1):70. doi:10.1186/s13023-021-01706-7



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