

Supporting Your Journey is Key

Better Communication While

Living With ATTR-CM

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Receiving a diagnosis of transthyretin amyloid cardiomyopathy (ATTR-CM) can be transformative for patients and their loved ones. Since the condition is associated with heart disease, changes to lifestyle may be needed. Empowerment and the support of caregivers can be important during a patient's journey.

Patient Engagement and Empowerment

Many people with ATTR-CM have undergone a long diagnosis journey, even when there is a family history of the disease. When diagnosed at a later stage, patients and caregivers can be pushed into new territories in managing the disease.¹ Engaging specialists and being transparent about how signs and symptoms are impacting work, daily activities, and relationships are important. Managing ATTR-CM can be overwhelming, and it is important to have one's social, emotional, and physical needs met. Some aspects of empowerment include:

- Working with advocacy groups and rare disease organizations to learn more about the condition
- Having a list of questions prior to every medical appointment and being certain to receive and understand the answers
- Explaining one's personal treatment goals and making a plan with the care team to help reach them
- Receiving referrals for specialist care when needed, such as for genetic testing and mental health

Communication and Support

Having open and transparent lines of communication with a caregiver is important. Some points to keep in mind about connecting effectively with caregivers include:

- The need to build trust and set clear physical and emotional boundaries for everyone
- Being candid about how symptoms are affecting daily life
- Knowing when and how to ask for help with household chores, appointments, and treatment plans

Mental Health

With a condition that affects so many aspects of life, it's understandable to experience feelings of stress, anxiety, and depression. Reaching out for support isn't always easy to do; however, there is help available. An ATTR-CM care team may be able to recommend a mental health professional, respite care, in-home care, or a social worker. Patient advocacy groups are another excellent place to make connections with other patients and caregivers, and serve as a trusted source for disease information.

Living With ATTR-CM

A diagnosis of ATTR-CM can be challenging for a family. Keeping open lines of communication can be an important factor in helping to preserve emotional and social well-being. Living a life of fulfillment while coping with a rare condition is helpful with caregiver support, and mental wellness.

Support is Key to Emotional Wellness

Patient Engagement

Learning about ATTR-CM, being transparent about signs and symptoms, setting goals

Patient Empowerment

Requesting referrals for specialists, learning about the disease and treatment, defining personal goals

Caregiver Communication

Building trust, setting boundaries, sharing responsibilities

Mental Health

Contacting advocacy groups, seeking therapy, coordinating respite care

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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