

SUPPORT YOUR LOVED ONE

with ATTR

Discover
ways to care
for someone
living with ATTR
amyloidosis (ATTR)
and yourself.

IRV, living with
wild-type ATTR, and
REBECCA, his spouse
and caregiver





REVEALING YOUR ROLE AS A CAREGIVER

When a loved one has been diagnosed with ATTR, the symptoms that can come with the disease may require someone, like you, to become a caregiver.

We're here to help. This guide provides helpful tips and information to help you be the pillar of strength and support your loved one's needs.

Go beyond the surface of ATTR

In addition to being a source of physical and emotional support, you play an important role in advocating for the health and well-being of someone living with ATTR. Becoming a caregiver is a significant responsibility and can present challenges that require lifestyle changes.

An important step as a caregiver is to understand the disease—how it develops and how it affects patients—so you can help monitor your loved one's condition and communicate effectively with their doctor. Having informed conversations about the disease will better prepare you for the journey ahead.

Discover more about ATTR with the Educational Overview Brochure at ATTRrevealed.com/brochure

Staying organized is key

ATTR affects several parts of the body, so your loved one living with the disease may see several doctors, including a primary care doctor, cardiologist, and neurologist. To stay organized for these visits, consider creating a **Health Record**.

Life can get hectic, and it can be easy to forget to mention a symptom, concern, or condition the person that you're caring for may have when meeting with their doctor. A **Health Record** will help you stay focused during the visit so you can advocate for your loved one's health.

Creating a Health Record

Working with your loved one to create and maintain a **Health Record** can help ease the stress of preparing for an appointment. It can also make it easier for someone else to step in as a caregiver when you're taking personal time for self-care or if you suddenly become unavailable.

What to include:

- **List of symptoms:** Keeping track of all symptoms, even if they seem minor or unrelated, can make it easier when talking to a doctor about managing the disease
- **Medical history:** Include any important information related to medical history, including current and past diagnoses, surgeries, or other medical conditions
- **List of medications:** Keep a diary or log of all medications so you can provide this information to the healthcare team without relying on memory
- **Contact information:** Keep all relevant contact information in one spot for quick access, including doctors, insurance, support groups, family members, and emergency contact information

Reveal more with the Symptoms Tracker & Checklist
at ATTRrevealed.com/tracker



CECE, living with
hereditary ATTR

Helpful tips for you

LEARN ABOUT ATTR



Knowledge is power. Educating yourself about the disease can help you have informed conversations with your loved one and their healthcare team.

HAVE AN OPEN DIALOGUE



Communication is one of the most important elements of caregiving, as it helps form a stronger bond between you and your loved one. Open communication with the healthcare team is also vital to managing their health.

TAKE TIME TO CARE FOR YOURSELF



It's important to look out for your own well-being when taking care of others. Try to interact socially outside the caregiving environment and continue to focus on your own health with exercise, sleep, and a balanced diet.

BE VOCAL



Living with ATTR can be both physically and mentally exhausting, and it can get overwhelming to communicate with the healthcare team. When caregivers and advocates speak up, it can help the doctor with making decisions on how to manage the disease. If you notice seemingly unrelated symptoms affecting multiple parts of the body that your loved one is struggling with, speak up. Every bit of information counts.



JERRY,
living with wtATTR

Discussing your circumstances

The responsibility of being a caregiver can sometimes require adjustments to your schedule, your routine, and your life in general. Discussing your caregiver role with others can help you manage your daily life and help others understand what you and your loved one are experiencing.

Here are some suggestions about how to talk about the disease and your role as a caregiver:

“

A person who is close to me has a condition that affects their ability to perform daily tasks on their own.

“

The disease can make daily activities difficult—it can be hard to make commitments because I never know if it will be a good or bad day for them.

“

I may need to provide transportation or attend doctor's appointments with them, so I might not always be available.

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Support beyond friends and family

Whether you and your loved one are starting your ATTR journey or have been managing the disease, there are helpful resources and support for you.

Visit ATTRrevealed.com/resources for more helpful tools and information, including a list of support groups and foundations.



MICHAEL,
living with wtATTR

CECE,
living with hATTR



Scan the code or visit
www.ATTRrevealed.com to
learn more about ATTR and take
advantage of other resources.



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