Alnylam ASSIST®

Patients With Rare Disease: A Caregiver's Guide

Supporting You and Those Who Need You Most

Caregivers are key components in successful rare disease management. Alnylam Assist® helps patients and their caregivers with personalized support for Alnylam therapies throughout the treatment process.

Caregiving for Loved Ones With Rare Disease

How You May Help With Their Management

Caregivers often take on the significant responsibility of helping to manage the range of symptoms a loved one can experience as a patient with a rare disease.

As a caregiver, you may work closely with your loved one's healthcare team, patient support team, and advocacy organizations so that you and your loved one can make informed decisions together that work best for your family. Please note that you may need your loved one's permission before you discuss their condition with others.

Understand the Basics of the Rare Disease

Stay up to date on the basics of your loved one's rare disease, no matter how recently or how long ago it was diagnosed. There are many different causes of rare diseases. The majority are thought to be genetic, directly caused by changes in genes or chromosomes.

Be aware of the symptoms your loved one may experience so that you can keep track of their condition and help them communicate effectively with their healthcare provider, if necessary.

Your Loved One’s Team

Nobody Should Take This Journey Alone

Although helping to manage your loved one’s rare disease may feel overwhelming at times, your loved one has a healthcare team who will help you both navigate the challenges that can come your way.

Once your loved one has been prescribed an Alnylam therapy and enrolled in Alnylam Assist®, the Alnylam Assist® team can also support you and your loved one with appropriate resources.

A Customized Care Plan

Based on your loved one’s symptoms and overall health, their healthcare team will create a customized care plan.

Here’s what to consider if you are helping keep track of your loved one’s healthcare plan:

- The frequency and types of tests and procedures that may be needed and the accompanying appointments
- Important terms and definitions you may hear from your loved one’s healthcare team when discussing how they monitor your loved one’s condition or treatment progress
- A consolidated list of your loved one’s doctors, specialists, and other healthcare professionals

Success as a Caregiver

The More You Know, the Better

Keep up to date about your loved one's rare disease. By continually educating yourself, you can have more informed conversations and help support them in their journey ahead.

Knowing as much as you can about your loved one's condition and symptoms can make you better prepared to communicate with doctors and other healthcare professionals, if you have permission to do so.

Communication Is Key

Communication is one of the most important elements of caregiving. Talking with your loved one may help you form a stronger bond and enable you to share insights with doctors about their health and well being, if you have permission to do so.

Additionally, be open and honest about your state of mind as well. Having a strong support network can help you with your own emotional journey.

Keeping Track and Talking With Others

Tracking Symptoms and Treatment

Take note of your loved one's symptoms since they can vary depending on circumstances. Be aware of their response to treatments and any side effects. This information can help to better guide any conversations you may have with doctors about your loved one's condition. Remember, you may need permission to discuss your loved one's condition with anyone else.

Explaining Circumstances to Others

As a caregiver, life situations may arise for your loved one at work, school, or doctor's appointments that may require discussion. Here are some sample statements to consider, depending on the situation:

- *"My loved one has a rare disease with symptoms that can cause us to need a little more time to get there"*
- *"We might not always be available because my loved one has frequent doctor's appointments"*
- *"Some symptoms can make certain daily activities difficult"*
- *"My child may need more flexibility with school attendance and scheduling"*

For Caregivers of Young Children

Engaging With Your Child

Talk to your child about their condition
Help them understand why managing their rare disease is important and how they can stick to "the plan." Help your child stay motivated by teaching the importance and value of care.

Make rare disease management feel normal
Help your child feel as comfortable as possible if treatment is being received in a facility. Bring activities, games, or books that can help calm or distract your child.

Teach the importance of taking care of body and mind
Create an environment where your child can keep their body strong by eating healthy foods, playing with friends, and getting a good night's rest.

Additionally, let them know that it's okay to feel tired, angry, or sad about having a rare disease, and that they can talk to you whenever they need to. Assure them that you will do whatever is necessary to help keep them safe.

Helping your child succeed
Have a solid routine to help children stay on top of managing their rare disease so that they can stay involved with the things they love.

Helping Your Child With the Doctor

Engaging With the Doctor

Going to the doctor's office may feel intimidating for children. Help them understand that the doctor is on their side, and even though going through different tests and procedures feels intrusive, it's necessary for their proper care.

Let your child ask the doctor any questions so that they can feel like they are part of their disease management plan.

Preparing for Your Child's Appointment

- **Ask** the doctor if there's anything your child needs to do beforehand
- **Record** any symptoms, even if they seem unrelated to the rare disease
- **Make** a list of all medications, vitamins, or other supplements your child takes
- **Write** down questions to ask their doctor

If your child has been diagnosed with a hereditary disease, talk with your doctor about how this may affect other members of your family.

You Are the Strongest Part of Your Loved One’s Support System

How to Care for Yourself Through the Process

As a caregiver who deals with the complexities of caring for a loved one with a rare disease, it’s important to remember your own well-being.

Practice self-care
It takes time, energy, and perseverance to care for someone you love who is living with a rare disease, but don’t forget to take care of yourself. Remember to make time for your health with exercise, proper sleep, and a balanced diet.

Be sure to interact socially outside of the caregiving environment. It is important to have people in your life (friends or support groups) who understand or can relate to your situation. Remember to set aside time for yourself and look out for your own well-being.

You Are the Strongest Part of Your Loved One's Support System

Expand Your Circle of Support

Whether your loved one is a child or an adult, it's important to know who interacts with them regularly (such as teachers, employers, friends, or babysitters) and help them understand your loved one. That way, the responsibility isn't all on you to ensure your loved one is taking all the necessary precautions to stay healthy.

By communicating your loved one's unique needs to others, you can expand the network of knowledgeable people looking out for your loved one's well-being. Please remember to first get permission from your loved one to discuss their health status with others.

Seek Support

Advocacy and support groups are available nationally and locally to provide you with a network of people who may have similar questions, concerns, and caretaking experiences.

National Organization for Rare Disorders
www.rarediseases.org

Global Genes
www.globalgenes.org

National Alliance for Caregiving
www.caregiving.org

Caregiver Action Network
www.caregiveraction.org

The Alnylam Assist® Support Team

What Is Alnylam Assist®?

The Alnylam Assist® support program offers comprehensive personalized services for patients receiving Alnylam therapies throughout their treatment process. This includes helping them understand insurance coverage and financial support options for which they may be eligible, as well as providing educational materials to help inform you and your loved one if they are requested.

Case Managers

When loved ones begin treatment, they will be partnered with their own dedicated Case Manager. Case Managers are experienced in helping individuals get started on treatment, navigating insurance benefits, and providing tailored support. They will adjust their level of contact based on the personal preferences of your loved one.

Patient Education Liaisons (PELs)

PELs have backgrounds in nursing or genetic counseling and are experienced in educating patients and their families about matters related to rare diseases. PELs can help you in a variety of ways, including providing disease and product education, connecting you to additional resources, and answering questions about treatment.

☎ To reach a dedicated Case Manager, call **1-833-256-2748** Monday–Friday, 8am–6pm ET.

Remember, you must have your loved one's permission to have discussions on their behalf with a Case Manager.