

# Caregiver Focus: Rare Diseases

Caring for someone with a rare disease can feel isolating, but you aren't alone. Here, we offer resources and support to help navigate the road of rare disease caregiving.

By definition, rare diseases affect fewer than 200,000 people, according to the National Organization for Rare Disorders (NORD). So it's not surprising that being a caregiver for someone with a rare disease can feel isolating at times. Fortunately, awareness is spreading about not only people who have rare diseases but the caregivers who commit to making their lives better. Resources and support systems exist today that were nowhere to be found just a decade or two ago. Here's an important look at "rare caregivers," including a helpful list of 10 tips for those who are just starting their journey.

## Portrait of a Rare-Disease Caregiver

NORD notes that there may be as many as 7,000 rare diseases, so when it comes to caregivers, no two stories are alike. Tasks and challenges involved in caregiving differ from disease to disease and person to person. Although there is a variety of circumstances, caregivers for people with rare diseases do have some common experiences. A 2018 national study conducted by The National Alliance for Caregiving reports that rare disease has a "broad and lasting impact on caregivers, in both daily life and long-term well-being." Perhaps you see yourself in their study findings:

- Most rare caregivers are immediate family members and nearly all live in the same household as the person they care for.
- More than half reported feeling alone.
- 67% of rare caregivers say providing care to someone with a rare disease is emotionally stressful, which is twice as high as that of general caregivers.
- Four in ten report having fair or poor mental health.
- 37% report experiencing high physical strain.



## A Resource for Rare-Disease Caregivers

It's important to remember that just because the person you're caring for has a rare diagnosis, you are not alone. One helpful resource for rare caregivers is NORD, a nonprofit that helps caregivers understand their loved ones' conditions and how to advocate on their behalf.

## Newly Diagnosed Caregivers: Tips for Adjusting to the Role

If your family is dealing with a new diagnosis, try giving yourself and the person you're caring for time to adjust to a new reality that may be different than what you expected. The following ideas from NORD can help during that transition period.

- ✓ Learn about the disease. Knowledge is power! A good place to start is NORD's rare disease database.
- ✓ Seek out a medical expert who has treated other people with your family member's or friend's disease.
- ✓ Be the best advocate you can for the person in your care. Trust your instincts — ask for more testing, request more detailed explanations from doctors, and take time to paint a complete picture of your friend's or loved one's condition to any medical professional involved in treatment.
- ✓ Keep tabs on research. There might be current clinical trials for your friend's or family member's disease or condition.
- ✓ Educate others — especially medical professionals — by telling them about the rare disease and its effect on your lives. By doing so, you're improving public awareness of the disease.
- ✓ Play a role in public policy through NORD's Rare Action Network, which allows you to connect with other caregivers in your community and state.



### Rare Disease Day

The rare disease movement now has its own official day on par with campaigns for more common conditions (think Breast Cancer Awareness). Rare Disease Day takes place on the last day of February each year with the goal of raising awareness among policy makers, other decision-makers and the general public about rare diseases and their impact on patients' lives. Visit [rarediseaseday.org](http://rarediseaseday.org) to learn more and get involved in activities near you.

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**Sources:**

National Organization for Rare Disorders: Rare disease facts

<https://rarediseases.org/wp-content/uploads/2019/02/nord-rareinsights-rd-facts-2019.pdf>

National Alliance for Caregiving: Rare disease caregiving

<https://www.caregiving.org/rare/>

National Organization for Rare Disorders

<https://rarediseases.org/>

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