

RARE FAMILIES, REAL LIFE

RARE DISEASE CAREGIVERS ARE UNSUNG HEROES

Caring for someone with a rare disease touches all aspects of life.



8.9 years

average time a rare caregiver spends caring for their loved one

Over **21%** are caregivers for 15+ years



RARE DISEASE

Any condition affecting less than 200,000 people in the U.S. There are ~7,000 rare diseases. Most do not have FDA-approved treatments



RARE CAREGIVER

Family or friend who provides unpaid care to one of the 25 million Americans living with rare diseases

RARE CAREGIVING IS A FULL-TIME UNPAID JOB

62% care for a child with rare disease

53 HOURS/WEEK

38% care for an adult with rare disease

37 HOURS/WEEK

59% receive help from an unpaid caregiver

A quarter of the time a teenager or child is the helper.

67% find rare caregiving stressful

More than **50%** of rare caregivers:

- Have challenges caring for their own health
- Have difficulty making friends

94% take pride in their role as a caregiver



Rare caregiving impacts their home, school, and work lives — and the healthcare system is challenging.

89% have to educate healthcare professionals about the rare condition

31% have issues accessing treatments

67% don't feel their local hospital can handle the rare disease

65% work while providing care

91% have gone in late or left work early to provide care

45% have cut back on their hours

Rare caregivers often struggle to fulfill their school responsibilities

86% have experienced financial hardship