Impact of Rare Disease on Caregivers

While the diseases are rare in prevalence and cross many therapeutic areas, in total, a rare disease affects one in 12 Canadians.

Treatment, knowledge and support for these diseases are limited and a result, patients and their caregivers face many barriers.



Caregiver Profile



3 out 4 are parents caring for their child with a rare disease



86% of caregivers identified as female

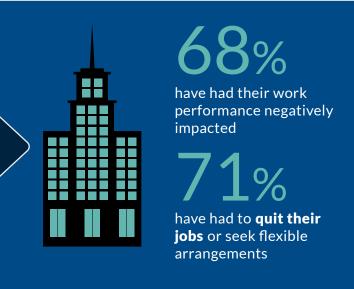


Majority
suffer from financial hardship

& 3 out of 4 feel socially isolated from friends and family

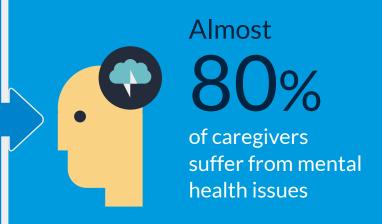
Rare diseases don't only impact patient lives, but families and communities too. While caregivers do all they can for their loved ones, they often face financial stress and increased strain on their mental health.







Financial burden experienced as a result of caregiving responsibilities also leads to mental health issues such as social isolation and stress



58% have lost relationships

have strained relationships

Half of caregivers are only able to engage in social activities less than once a month

Caregivers are doing all they can...

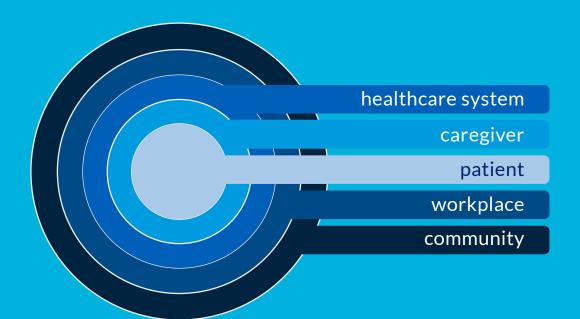
"Raising Hope has completely changed my perspective on life. She has made me stronger and I am working tirelessly every day to do the same for her."

Abbey-LayneMother of Hope,
child living with Cystic Fibrosis



feel unsupported by Canada's healthcare system and almost 3/4 say there has been no improvement in treatment options.

The Range of Rare Disease: Who and What It Impacts



There are glaring gaps in support around the financial hardships and mental health issues that caregivers face. In order to meet the needs of this dedicated yet vulnerable group, the realization of a national rare disease strategy developed in partnership with patients and caregivers is needed to help ease the burden on these families.

2019 Canadian Impact of Rare Disease Survey

raredisorders.ca