

# 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 as a result, patients and their caregivers face many barriers.



## Caregiver Profile



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

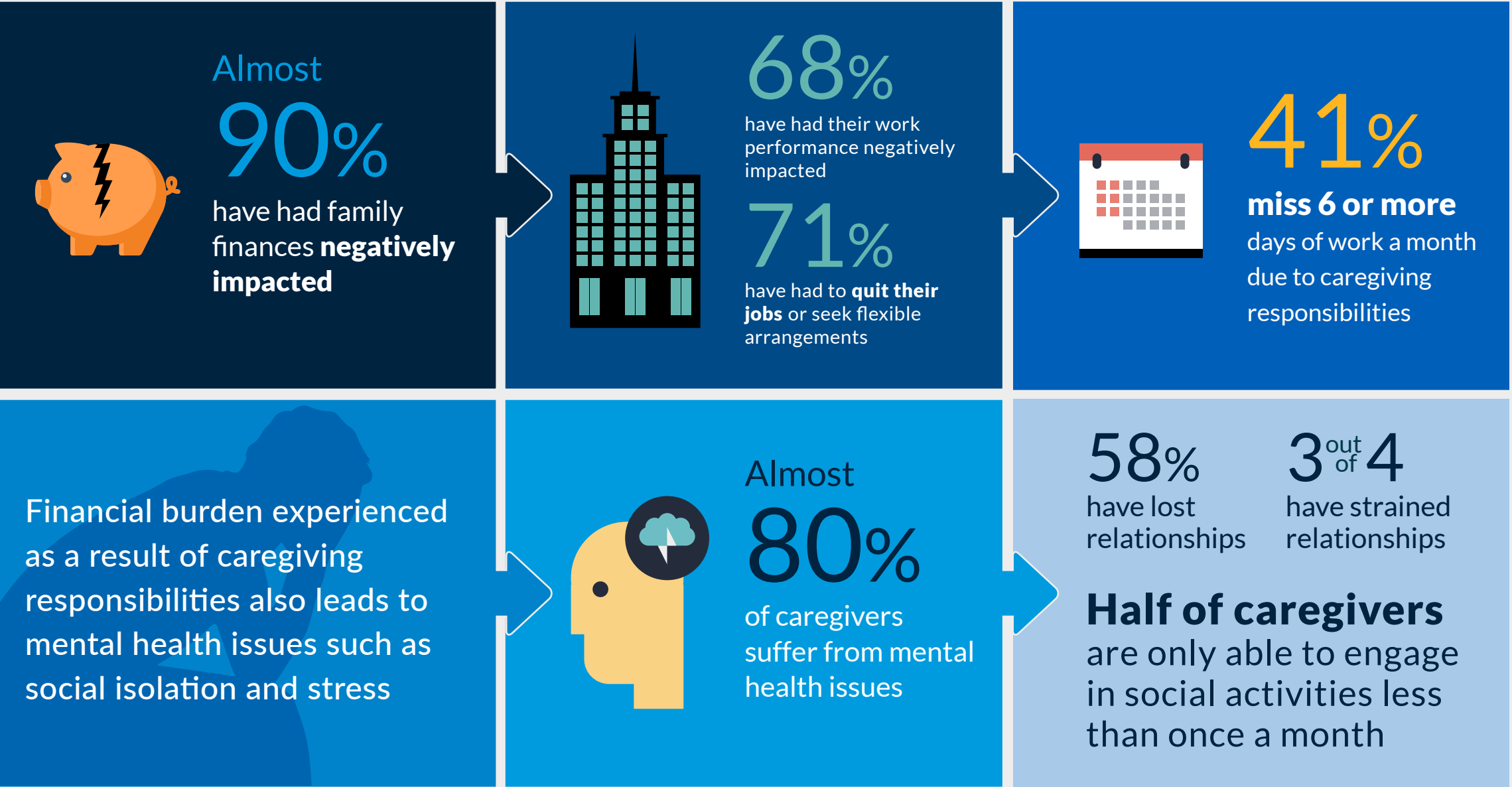


**86%**  
of caregivers identified as female



**Majority**  
suffer from financial hardship & 3 out of 4 feel socially isolated from friends and family

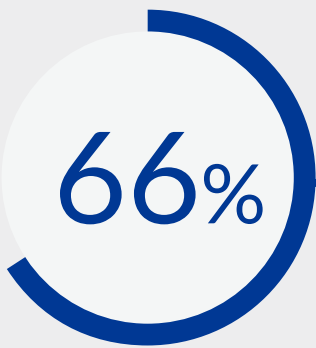
Rare diseases don't only impact patient lives, but families and communities too. While caregivers do all they can for their loved ones, they often face financial stress and increased strain on their mental health.



Caregivers are doing all they can...



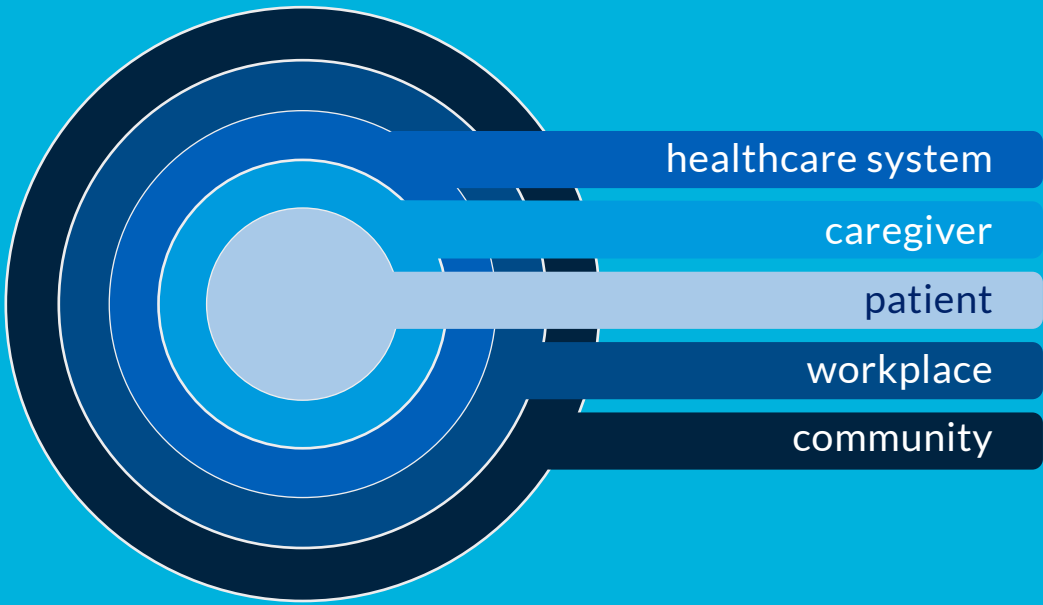
...but



feel unsupported by Canada's healthcare system and almost  $\frac{3}{4}$  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.