

Impact on patients and caregivers

Patient advocacy group Rainbow Across Borders spoke to 152 people who are coping with rare diseases. Here are some of the findings.



Seven in 10

patients or caregivers said they often feel stressed, anxious or frustrated about the illness.

Eight in 10



said that the financial cost of managing the illness is a substantial burden to them and their families.

Two out of three

said that the financial support they get is not enough to help them cope with paying for treatment and other aspects of disease management.



The majority said that a counselling service would help, although **two out of three**

said emotional support and counselling were not made available when they were diagnosed.



Seven in 10

said that a caregiver has had to give up his career to look after them.