Survey of Childhood Cancer Survivors & Caregivers

A study of patient needs and challenges

These are key findings from a joint online survey conducted in both 2017 and 2018 by the Children's Cause for Cancer Advocacy and the Patient Advocate Foundation.

SURVIVORSHIP

- 60% of childhood cancer families surveyed either don't have a written survivorship care plan or are unsure if they do.

Follow-up care plans are a critical tool for transitioning care to adult providers and managing long-term side effects.

- One in four survivors report that the cost of their cancer-related medical care impacted their ability to attend their college or university of choice.

- 30% of survivors report that the cost of their care impacted their career course or job choice.

In 2018, we asked survivors:

In the last 12 months, how often did your general practitioner seem informed and up-to-date about the care you received from cancer specialists?

3-in-10 answered never or almost never.

FINANCIAL HARDSHIP

"As a middle class family with insurance we do not qualify for any aid or assistance from anywhere. We owe over $100,000 in medical debt, plus regular debt and lost wages. We will likely file bankruptcy in the next 6 months."

- Parent of a child with cancer

60% of families have experienced a financial hardship related to the cost of their child's care in the past year. One-third of families with a hardship characterize it as extremely severe and unable to manage.

HARDSHIPS GO UNADDRESSED

Q: At any point in your child's care, were you asked about any financial hardships your family may be experiencing related to food, energy or housing?

A: 55% answered no.