


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

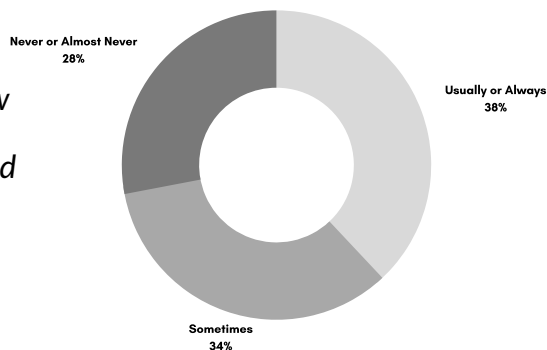
 60% of childhood cancer families surveyed either don't have a written survivorship care plan or are unsure if they do.

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.**

COVERAGE CHALLENGES

Among caregivers surveyed in both 2017 and 2018, **one-third** reported insurance denials for treatment. The impact of those denials ranged from...

INTERRUPTING OR CHANGING THE COURSE OF A CHILD'S TREATMENT

"We had to get a special approval override from our insurance to get our child the specific chemo med she needed. It caused several days of stress and delayed treatment as we tried to get the override. It was very scary and stressful to know we couldn't afford the med our child needed to live and that the insurance might not pay."

"One drug was never approved under compassionate use despite my daughter's desperate and urgent need for it to save her life. She lost her life at the age of 7 within a month after this drug was denied."

HIGH OUT-OF-POCKET EXPENSES

"The insurance only covered 7 prescription pills for nausea in a month but my child needed 2 pills every day. It was a new medication with no generic option, and a large expense."

NAVIGATION TIME & STRESS

"Our treatment hospital is in network for treatment but out of network for diagnostics requiring lots of back and forth and pre-approvals. I have lost a fair amount of sleep in the process and worried about the potential for big bills."