

Survival at All Costs

A Family Reach Report on the
Financial Burden of Cancer



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Angel's Story

Angel was a bright, energetic boy with an even brighter future. Shortly after Angel turned two, he was diagnosed with stage IV neuroblastoma. Angel's world quickly changed – days that were once spent playing outside now required long hours in the hospital. For Angel's parents, Alma and Rodolfo, many sacrifices ensued; Alma withdrew from college and Rodolfo was forced to miss work in order to care for their children. They spent long hours and financial resources on the commute back-and-forth to Angel's treatment center. The family was also emotionally devastated. As Alma explained, "It was the worst news of my life...all our dreams and future plans were put on hold."

BACKGROUND

Stories of family sacrifice like Angel's are commonplace in the pediatric cancer world. In 2015, the American Cancer Society (ACS) estimated that 10,380 families with children under the age of 15 will face a pediatric cancer diagnosis. While treatment advances have improved five-year survivability rates to more than 80%, cancer still represents the second leading cause of death for children in the United States. Evidence also suggests that childhood cancer rates have risen in recent decades. While the child's death is the greatest risk of a cancer diagnosis, the second-greatest danger may be financial catastrophe. An evaluation of pediatric illness expenditures revealed that cancer hospitalizations cost five times as much as hospitalizations for other complex chronic conditions, with childhood cancer costs reaching almost \$32,000 more per hospital stay. In fact, a national survey of medical bankruptcy filers found that 14.6% of respondents indicated the patient was a child.

Despite facing immense adversity both emotionally and financially, parents of children with cancer display great resilience and strength. Parents' ability to address the financial burden of their child's diagnosis, however, is often complicated by their caregiver responsibilities. Employment interruption, income losses, and inability to perform basic domestic or parenting duties for other siblings compound an already emotionally-taxing situation for parents of children with cancer. Many parents face difficult financial decisions that may leave the family financially strained in the long-term. Family Reach believes that flexible, timely financial assistance represents the key to helping parents weather the caregiving storm. This paper will explore the financial struggles of families facing pediatric cancer, financial coping strategies employed by parents, and the role of Family Reach's unique financial lifeline in helping to ease the financial burden for these families.



CAREGIVER RESPONSIBILITIES AND COSTS

Following a child's cancer diagnosis, parents grapple with the life-threatening nature of their child's illness and adjust to a new set of caregiver roles. Caregiver responsibilities for parents whose children have cancer are numerous, time-consuming, and both physically and emotionally taxing. A qualitative study of contextual life stressors for parent caregivers in Canada revealed that caregivers categorized their duties into three distinct tasks: providing emotional support to both children and other family members, seeking treatment-related information and resources to manage medical and day-to-day costs, and physically performing medical tasks to care for their sick child and other siblings.

One Family Reach grant recipient described devoting all of her free time to financial resource-finding, but she secured financial assistance only after months or even years of persistent effort.

Previous attempts to measure the resources required to respond to a pediatric cancer diagnosis generally examined two cost categories: direct costs and indirect costs. Direct costs are defined by any costs relating to treatment, including insurance payments and other out-of-pocket costs directly contributing to patient access to treatment (travel, food, lodging, child care, etc.). Indirect costs include monetary losses incurred by families either because of productivity loss, employment loss, patient and caregiver time, and the years of potential life lost in the event of a child's death.

Additionally, managing the caregiving duties for a pediatric cancer diagnosis comes with other, less tangible costs. Researchers in Canada noted that household income directly influenced caregiver strain, which in turn influenced both the physical and psychosocial quality of life of parents. Another study noted that parents experiencing negative financial life events were five times more likely to report clinically depressive symptoms. The quality of life reduction risk for parents is particularly troubling considering a caregiver's physical and mental state also impacts the wellbeing of patients. In short, the new caregiver role necessitated by a pediatric cancer diagnosis costs families directly through medical expenditures, indirectly through time and opportunity costs, and intangibly through diminished quality of life for family members.

Employment Interruption and Income Loss

With their expanded caregiver responsibilities, many parents face cutting back or leaving employment to free up time to devote to caregiving. A literature review of childhood cancer studies found that 77 to 84% of parents faced some sort of work interruption. Work interruption constitutes not only of quitting or losing a job, but also missing work, scaling back hours worked, declining educational or work advancement opportunities, or sacrificing overtime. A study of families facing advanced pediatric cancer revealed 94% of parents experienced work interruption in one or more of these forms. This figure is not surprising when we consider the results of another study which showed parents missed an average of 17.3 days of work in the first month following their child's diagnosis. In some studies, families needed one parent to quit his/her job to assume full-time caregiving responsibilities at rates as high as 36%. Employment interruption and instability during the first five years following a child's diagnosis have shown to increase parents' self-reported financial burden.



For the majority of families, income loss is a very real side effect of employment interruptions. A meta-analysis of financial burden in pediatric cancer demonstrated that upwards of 60% of families lose more than 10% of household income, and nearly 20% lose more than 40% of household income. In some cases, the income loss due to employment interruption is so dramatic that families drop below the federal poverty line. ACS estimates that two high cost points exist in the trajectory of a cancer patient's life: shortly after diagnosis and again when patients need assistance managing late-effects of treatment. The family faces a two-fold financial vulnerability following their child's diagnosis—while medical costs reach an all-time high, caregiving responsibilities disrupt the availability of resources needed to respond to the financial burden.



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Burdens for Rural Residents

For one in five families living in rural areas of the U.S., the time and money spent traveling to treatment centers offering specialized care required for their child's cancer add to the financial burden. In a study evaluating the impact of residence on caregiver burdens, rural families caring for a child with cancer had greater average out-of-pocket costs per visit than their urban counterparts (\$138 vs. \$42 respectively). The study also noted that longer travel times experienced by rural families resulted in a greater risk of the need for more expensive ambulatory care or emergency air transport. For 29% of families in the study, relocating closer to the treatment facility was a more viable financial solution than continuing to incur travel costs.

Travel time requirements also placed rural caregivers at increased risk of longer periods of employment disruption. Rural parents required to travel more than 2 hours to the treatment facility reported an average of 24 days of missed work in the first month following their child's diagnosis, with each hospital visit requiring a greater number of workdays missed compared to urban families. This evidence suggests that already limited caregiver time and financial resources for rural parents must stretch even further to accommodate their child's treatment.

Other Vulnerable Families

Additionally, studies have found that financial and caregiver burdens are more pronounced in low-income and lower-educated families, single-parent households, and families with additional siblings, thereby amplifying the vulnerability to financial crisis for these groups. Individuals from lower income and lower education strata may be more likely to occupy jobs with stringent policies about work absence and less flexibility to respond to caregiver demands without risk of imminent job or income loss. Meanwhile, single parents are solely responsible for managing all financial and caregiving needs for their families. The presence of additional siblings in a household generally leads to greater domestic labor (child care) costs to offset caregiving demands. Each of these factors decreases a family's ability to successfully avoid financial crisis caused by a child's cancer diagnosis.

CAREGIVER FINANCIAL COPING STRATEGIES

In the face of tremendous adversity, childhood cancer caregivers exercise a variety of financial coping strategies: parents reduce expenses by delaying big purchases; incur debt via credit cards, personal loans, and additional mortgages; sell property; pursue medical fundraising; and, at times, simply leave non-medical bills unpaid. A study in parents whose child died from his/her cancer found that 32% of participating U.S. parents were forced to use more than one financial coping mechanism during the course of their child's illness.

Financial coping for many families also meant sharing some of the caregiving or financial burdens with members of their support network. A study of childhood cancer families in Canada noted that families enlisted the help of an average of three individuals from within their family (grandparents, aunts, etc.) and two people in their wider support network (coworkers, church members, etc.). Researchers calculated the median direct and indirect costs to the entire family support network at about 4% of income after taxes. While financial coping strategies employed by parents are similar across all income levels, researchers warn that families with fewer resources or limited support networks will have less flexibility in how their household adapts financially. Additionally, researchers suggest that financial hardship is often forced on parents who lack the financial knowledge to implement healthy financial coping strategies.



Studies evaluating the major material hardships for families of children with cancer identified food, energy, and housing insecurity among the top three.

Housing Insecurity and Material Hardship

With an increased proportion of household income diverted to cover medical costs, families increasingly face budget shortfalls. Studies evaluating the major material hardships for families of children with cancer identified food, energy, and housing insecurity among the top three. According to a 2015 report from the Joint Center for Housing Studies at Harvard University, 25% of homeowners in the United States were considered "cost-burdened" (exceeding the 30% of monthly income spent on housing threshold), while nearly 50% of renting households were cost-burdened. The report also noted that almost a quarter of all renters are severely cost-burdened, spending over 50% of their income on housing costs. Thus, it comes as no surprise that the addition of medical costs and/or income loss in already cost-burdened families is a recipe for material or housing hardship.

The threat of homelessness or subsistence scarcity is a burden no family should bear, much less a family channeling their resources to support a child facing a life-threatening illness. Maintaining normal family rituals and routines is vital to the well-being of children and the family unit. A resource shortage in any of these material categories directly interferes with parents' ability to maintain a sense of normalcy for their household. Studies also show that acute resource shortages have a negative impact on health outcomes for cancer patients. Low income children and children from households reporting material hardship were more likely to experience acute and chronic side effects from their stem cell transplants than their counterparts without material hardships. Material hardship not only impacts the family's overall ability to cope under distressed conditions, but also interferes with a child's ability to physically tolerate treatment and make a full recovery.

A Dana-Farber study on children with acute lymphoblastic leukemia found a significant correlation between children living in high-poverty areas and early relapses from complete remission compared to those in low-poverty areas. Looking at 575 children over a 10-year period, the research concluded that of the children who relapsed in high-poverty areas (as defined by the US Census Bureau), 92 percent relapsed. Comparatively, only 48 percent of other relapsing children in more affluent areas relapsed early; in addition, “only 85 percent of high-poverty children lived for five years or more, compared with 92 percent of other children.”

Becca’s Story

Becca is an encouraging, compassionate child. She is the kind of girl who, as her mother explains, is “quick to defend others, loves to cuddle, and is eager to bring you a glass of ice water with a straw if she sees you’re having a hard time.” Becca was diagnosed with acute lymphoblastic leukemia when she was just five years old.

Becca’s mother, Kim, knew the diagnosis meant her family was in for a financial battle. Kim had dreams of studying law and attributes her negotiation skills with helping her manage the resource-finding for her family. She spent long hours on the phone trying to refinance the mortgage on their house and negotiating with gas and utilities companies just to make ends meet. For some types of assistance it took her almost one and a half years of persistent effort before the family could get access. Kim explained, “As a middle-income family, we were overqualified for a lot of assistance until my husband no longer had a job and at that point the circumstances were dire.”

Existing Resources

Kim’s experience with resource finding is common among families facing cancer. While a variety of resources currently exist to help families, the resources are fragmented, often address only one need, and vary in their eligibility criteria. Securing assistance therefore becomes a caregiver burden in itself; when a family experiences multiple needs, caregivers may be required to spend additional time searching for assistance from multiple sources and submitting multiple applications once eligibility is confirmed.

We will use the top three family material hardships (food, energy, and housing insecurity) to help illustrate this resource fragmentation and the challenges of resource finding for caregivers. Suppose a family of four is experiencing all three needs. A pediatric cancer resource guide produced by ACS lists four separate organizations providing food support, one source for energy support, and three potential resources (talking with a landlord or creditor, social worker, and the department of social services) for housing support. Identifying these eight

resources is just the first step of many. The caregiver would then need to confirm that his/her family meets eligibility requirements for assistance.

For example, the handbook recommends Temporary Assistance for Needy Families (TANF) for energy support. TANF provides federal grants to needy families, but requires that parents engage in work activities—a requirement that may be unsustainable for parents who must devote themselves to full-time caregiving. Likewise, the food supports listed (food banks, Women Infants and Children, Supplemental Nutrition Assistance Program, and school programs) vary in their eligibility criteria and may depend on availability within an individual's local community. Once the caregiver confirms his/her family is eligible for support, it is likely that he/she would be required to submit an application requesting assistance and subjected to a processing delay as the organization or agency responds to the request. The resulting process to secure resources that meet multiple family needs is time-consuming, cumbersome, and in addition to a parent's existing caregiver duties.

Family Reach: Filling Gaps

Family Reach was founded in 1996 by two families who experienced first hand the emotional and financial devastation of a pediatric cancer diagnosis. Informed by almost 20 years of experience working with families and leading hospitals and cancer centers, Family Reach has developed a continuum of direct assistance programs and support initiatives. The support programs at Family Reach are designed in direct response to the needs and resource-finding challenges experienced by families following a pediatric cancer diagnosis.

The most utilized assistance program at Family Reach, the Lifeline Grants program, provides streamlined, flexible grants to cover a wide range of household material hardships: mortgage, rent, utilities, transportation, car payments, lodging, food, childcare, etc. The application for parents is short and facilitated by a social worker, eligibility is simple (a cancer diagnosis, active treatment within the past year, and financial hardship due to cancer diagnosis), and application processing is designed to provide families with financial assistance within two business days. On occasion, Family Reach can fulfill crisis requests within 24 hours. Payments from the Lifeline Grants program are sent directly to the designated vendor/business removing the burden of follow up from the caretaker's responsibility. Lifeline grants range from \$250 to \$2,000 depending on family needs and allow families the flexibility to apply the funds where they need it most (Table 1). Understanding that needs may change during the course of a child's treatment, Family Reach also offers families the opportunity to re-apply for Lifeline grants as necessary.

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Table 1. Summary of Family Reach Grants, 2003-2015

Grant Purpose	Proportion of Grants Allotted to this Purpose	Grant Totals
Mortgage Assistance	20%	\$1,148,777.98
Rent Assistance	38%	\$1,862,927.21
Utilities	12%	\$387,282.32
Auto Expenses or Repair	8%	\$334,242.23
Medical Expenses	4%	\$183,567.16
Other Household Expenses	18%	\$763,974.31



Family Reach also recognizes that some families may be more susceptible to financial hardship during the course of their child's illness and may require ongoing help. To address this need, Family Reach created The Hands of Hope Grants program to respond to families experiencing catastrophic financial hardship (e.g. homelessness). Hands of Hope Grants are larger than \$2,000 and available over an extended period of time to provide more ongoing stability for families.

Historically, one in four grants at Family Reach supported single-parent families. However, single-parent households recently increased to 33% of 2015 grant recipients. Meanwhile, 50% of 2015 grant recipients earned less than \$25,000 annually and an additional 33% of families earned less than \$50,000. Family Reach also recognizes that some families may be more susceptible to financial hardship during the course of their child's illness and may require ongoing help. A crucial component of direct financial support for families seeking assistance from Family Reach is the provision of supplemental support through the distribution of gift cards for fuel, parking and general necessities to further address the need of families. Alleviating these everyday expenses can make a dramatic difference in the daily stress of families and directly impacts their ability to access care in a timely and safe manner.

Family Reach also provides indirect financial support through navigation services and a peer support program aimed at producing sustainable change for families. Within the Family Reach Navigation Support program, Family Reach social workers work closely with hospital-based oncology social workers, providing counseling, long-term planning and resource options for families seeking additional and/or alternative support outside of our foundation's resources and giving criteria.

Families and constituents report that the delivery of resources and support services by Family Reach produce sustainable change for those struggling with the financial burden of a pediatric cancer diagnosis due to a flexible, timely and collaborative model of assistance. Since its founding, Family Reach has provided financial, emotional and resource navigation support to more than 30,000 children and adults impacted by cancer. The flexible, diverse and timely support available through Family Reach helps to mitigate material hardship experienced by families while also alleviating many of the headaches of resource finding for caregivers.

CONCLUSION

A child's cancer diagnosis will dramatically impact a family's financial health. Parents respond to the danger to their child's life with a variety of coping strategies aimed at ensuring that their child has the best possible chance for survival. These financial coping strategies may require lifestyle shifts, employment and income loss, and often place the family at risk of material hardship and/or debt. The demands of caregiving also simultaneously limit parents' ability to respond to financial hardship. In most cases, financial burdens and caregiving demands are so great that cost sharing extends into the family's support network. Furthermore, existing resource fragmentation exhausts already limited caregiver time as parents struggle to identify and secure financial assistance for their families.

No family should have to face a child's cancer diagnosis, much less household or resource instability during a time of immense emotional turmoil. Through its innovative and flexible programs, Family Reach is able to respond to a diverse range of material, financial and emotional hardships quickly and efficiently. Family Reach is committed to supporting all families facing cancer regardless of income, and takes the extra step to serve vulnerable families through the provision of longer-term financial relief and navigation services.



Family Reach believes that every child deserves a fair shot at getting to the other side of cancer. By supporting the family that surrounds a child, Family Reach seeks to provide parents and loved ones the freedom to focus on what matters most — the health and survival of their child.



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SOURCES

- Anhang Price, R., Stranges, E., & Elixhauser, A. (2012). Pediatric Cancer Hospitalizations, 2009. HCUP Statistical Brief #132. Agency for Healthcare Research and Quality. Retrieved from <http://www.hcupus.ahrq.gov/reports/statbriefs/sb132.pdf>
- Bestvina, C. M., Zullig, L. L., & Yousuf Zafar, S. (2014). The implications of out-of-pocket cost of cancer treatment in the USA: A critical appraisal of the literature. *Future Oncology (London, England)*, 10(14), 2189-2199. doi:10.2217/fon.14.130
- Bona, K., Dussel, V., Orellana, L., Kang, T., Geyer, R., Feudtner, C., & Wolfe, J. (2014). Economic impact of advanced pediatric cancer on families. *Journal of Pain and Symptom Management*, 47(3), 594-603. doi:10.1016/j.jpainsymman.2013.04.003
- Bona, K., London, W. B., Guo, D., Abel, G., Lehmann, L., & Wolfe, J. (2015). Prevalence and impact of financial hardship among new england pediatric stem cell transplantation families. *Biology of Blood and Marrow Transplantation*, 21(2), 312-318. doi:10.1016/j.bbmt.2014.10.016
- Bona, K., London, W., Guo, D., Frank, D., & Wolfe, J. (2015). Trajectory of Material Hardship and Income Poverty in Families of Children Undergoing Chemotherapy: A Prospective Cohort Study. *Pediatric Blood Cancer*, 1-7. doi: 10.1002/pbc
- Children Diagnosed With Cancer: Financial and Insurance Issues. (2015, January 8). Retrieved from <http://www.cancer.org/acs/groups/cid/documents/webcontent/002594-pdf.pdf>
- Creswell, P. D., Wisk, L. E., Litzelman, K., Allchin, A., & Witt, W. P. (2014). Parental depressive symptoms and childhood cancer: The importance of financial difficulties. *Supportive Care in Cancer*, 22(2), 503-511. doi:10.1007/s00520-013-2003-4
- Dussel, V., Bona, K., Heath, J. A., Hilden, J. M., Weeks, J. C., & Wolfe, J. (2011). Unmeasured costs of a child's death: Perceived financial burden, work disruptions, and economic coping strategies used by american and australian families who lost children to cancer. *Journal of Clinical Oncology*, 29(8), 1007-1013. doi:10.1200/JCO.2009.27.8960
- Eyigor, S., Karapolat, H., Yesil, H., & Kantar, M. (2011). The quality of life and psychological status of mothers of hospitalized pediatric oncology patients. *Pediatric Hematology and Oncology*, 28(5), 428-438. doi:10.3109/08880018.2011.574202
- Fluchel, M. N., Kirchhoff, A. C., Bodson, J., Sweeney, C., Edwards, S. L., Ding, Q., . . . Kinney, A. Y. (2014). Geography and the burden of care in pediatric cancers. *Pediatric Blood & Cancer*, 61(11), 1918-1924. doi:10.1002/pbc.25170
- Granek, L., Rosenberg-Yunger, Z. R. S., Dix, D., Klaassen, R. J., Sung, L., Cairney, J., & Klassen, A. F. (2014). Caregiving, single parents and cumulative stresses when caring for a child with cancer. *Child Care Health and Development*, 40(2), 184-194. doi:10.1111/cch.12008
- Himmelstein, D., Thorne, D., Warren, E., & Woolhandler, S. (2009). Medical Bankruptcy in the United States, 2007: Results of a National Study. *American Journal of Medicine*, 1-6. doi:10.1016/j.amjmed.2009.04.012
- Joint Center for Housing Studies at Harvard University. (2015). *The State of the Nation's Housing*. Retrieved from <http://www.jchs.harvard.edu/sites/jchs.harvard.edu/files/jchs-sonhr-2015-full.pdf>
- Klassen, A. F., Raina, P., McIntosh, C., Sung, L., Klaassen, R. J., O'Donnell, M., . . . Dix, D. (2011). Parents of children with cancer: Which factors explain differences in health-related quality of life. *International Journal of Cancer*, 129(5), 1190-1198. doi:10.1002/ijc.25737
- Lau, S., Lu, X., Balsamo, L., Devidas, M., Winick, N., Hunger, S. P., . . . Kadan-Lottick, N. (2014). Family life events in the first year of acute lymphoblastic leukemia therapy: A children's oncology group report. *Pediatric Blood & Cancer*, 61(12), 2277-2284. doi:10.1002/pbc.25195
- Mayberry, L., Shinn, M., Gibbons Benton, J., & Wise, J. (2014). Families Experiencing Housing Instability: The Effects of Housing Programs on Family Routines and Rituals. *American Journal of Orthopsychiatry*, 84(1), 95-109. doi: 10.1037/h0098946.
- Nipp, R. D., Powell, E., Chabner, B., & Moy, B. (2015). Recognizing the financial burden of cancer patients in clinical trials. *Oncologist*, 20(6), 572-575. doi:10.1634/theoncologist.2015-00689
- Rosenberg-Yunger, Z. R. S., Granek, L., Sung, L., Klaassen, R., Dix, D., Cairney, J., & Klassen, A. F. (2013). Single-parent caregivers of children with cancer: Factors assisting with caregiving strains. *Journal of Pediatric Oncology Nursing*, 30(1), 45-55. doi:10.1177/1043454212471727
- Syse, A., Larsen, I. K., & Tretli, S. (2011). Does cancer in a child affect parents' employment and earnings? A population-based study. *Cancer Epidemiology*, 35(3), 298-305. doi:10.1016/j.canep.2010.08.002
- Temporary Assistance for Needy Families (TANF). (2015, October 29). Retrieved from <http://www.acf.hhs.gov/programs/ofa/programs/tanf>
- Tsimicalis, A., Stevens, B., Ungar, W. J., Greenberg, M., McKeever, P., Agha, M., . . . Moineddin, R. (2013). Determining the costs of families' support networks following a child's cancer diagnosis. *Cancer Nursing*, 36(2), E8-E19. doi:10.1097/NCC.0b013e3182551562
- Tsimicalis, A., Stevens, B., Ungar, W. J., McKeever, P., & Greenberg, M. (2011). The cost of childhood cancer from the family's perspective: A critical review. *Pediatric Blood & Cancer*, 56(5), 707-717. doi:10.1002/pbc.22685
- Warner, E., Kirchhoff, A., Nam, G., & Fluchel, M. (2014). Financial Burden of Pediatric Cancer for Patients and Their Families. *Journal of Oncology Practice*, 1-7. doi: 10.1200/JOP.2014.001495
- What are the key statistics for childhood cancer? (2015, January 13). Retrieved from <http://www.cancer.org/cancer/cancerinchildren/detailedguide/cancer-in-children-key-statistics>
- Whitney, R. L., Bell, J. F., Reed, S. C., Lash, R., Bold, R. J., Kim, K. K., . . . Joseph, J. G. (2015). Predictors of financial difficulties and work modifications among cancer survivors in the united states. *Journal of Cancer Survivorship : Research and Practice*, doi:10.1007/s11764-015-0470-y [doi]
- Yabroff, K. R., Lund, J., Kepka, D., & Mariotto, A. (2011). Economic Burden of Cancer in the US: Estimates, Projections, and Future Research. *Cancer Epidemiology, Biomarkers & Prevention : A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology*, 20(10), 2006-2014. doi: 10.1158/1055-9965.EPI-11-0650