

A Child's Cancer Diagnosis Launches Families Into Emotional and Financial Turmoil

The National Children's Cancer Society Outlines Resources for Help and Support

The list of challenges faced by a family with a child who has just been diagnosed with cancer is endless. Parents are launched onto an emotional rollercoaster as they try to cope with the devastating news. Everyone hears about children getting cancer and it breaks their hearts; when it happens to your own child, it's incomprehensible. And there's no time to process the heartache and fear, as parents must immediately start meeting with multiple doctors, learning complex medical terms and planning rigorous treatments.

While their one child faces unknown pain and suffering on the road to getting well, the rest of their family is also thrown into disarray. Mom and dad must divide up the caretaking, with one often traveling far from home for treatment with their sick child. Relatives might have to be called in to help with babysitting and getting other children to school or sports, and siblings often struggle with the upset in their family.

When a child gets cancer, it's a crisis for the whole family, according to the [American Cancer Society](#). Every other facet of life takes a back seat as everyone focuses on the little boy or girl who is critically ill.

On top of it all, for most families, finances are strained to the breaking point as the medical bills fill the mailbox daily.

"Cancer breaks up families, it puts pressure on all the existing cracks," says father of seven Todd Thornock, whose son Malcolm was diagnosed with stage four neuroblastoma at age four. "I understand why...our world was turned upside down." Thornock said that he and his wife had a healthy system of communicating about "the hard things in life," so their relationship wasn't as strained as it could have been while their son was sick, but their family was separated for as long as ten days at a time and finances were strained. Even still, he met other families that struggled much more.

Malcolm is now seven and getting ready to enter second grade. He had chemotherapy and radiation at the University of Iowa Children's Hospital followed by specialized treatment at Memorial Sloan Kettering Cancer Center in New York City. He still travels regularly to Sloan Kettering but has been clear of cancer for 18 months and off treatment for more than a year. He's active and busy like any other seven-year-old, although he has some growth and strength problems as a result of radiation and chemotherapy.

Thornock and Ashley Fraser, whose daughter Lexi was diagnosed with cancer last December just before her second birthday, agreed that one of the best things families can do is take advantage of every resource available to support them.

"In the beginning, I was so protective of both my kids. I wanted to do everything myself and didn't want any help," recalls Fraser. Her new son was only six months old when Lexi got sick in 2014. Lexi needed surgery to remove a kidney, and then underwent chemotherapy followed by long hospitalizations in isolation rooms because she kept getting infections. Fraser would often spend a week or more alone at Lexi's side, while her husband and mother were at home taking care of their son. "The further into treatment we got and the sicker Lexi got, the more damaging it was to all three of us. My husband and I learned its okay to get help – even though you may not want it."

Lexi's diagnosis was definitely a crisis for Fraser and her husband, Chris. Fraser had taken her daughter to the pediatrician for a well-child visit, and looking back she's grateful the doctor caught the cancer early. But it was a total shock. Lexi was diagnosed on a Friday afternoon, hospitalized through the weekend and in surgery to remove a kidney on Tuesday.

"It was such a lot for both of us to learn," said Fraser "And in the beginning there was so much going on – surgery, radiology, oncology and clinic. It was overwhelming."

Fraser took a leave from her job as a nurse to stay with Lexi at the hospital while her husband continued to juggle his career along with caring for their infant son and occasionally relieving his wife at Lexi's side. Even when Lexi was able to come home, she would be sick through the night, requiring constant care and exhausting her mom.

Thornock, an Iowa State University accounting professor, was able to work from Malcolm's hospital room much of the time. But that treatment center in Iowa City was more than two hours from their home, so his wife was left alone to care for the other five children they had at the time Malcolm was undergoing treatment (they've since added a seventh child to their family.)

"Because the treatments would take anywhere from three to ten days and someone needed to be with him all the time, it meant one of us was away from home, and that dynamic is really difficult with a large family," Thornock said.

For some families, an initial challenge may be finding guidance on where to take their child for treatment. Both the National Cancer Institute and the American Cancer Society recommend that children with cancer be treated at childhood cancer centers. These centers, most of which are part of the NCI-supported [Children's Oncology Group](#) (COG), use a comprehensive team approach to treating pediatric cancer. The team includes doctors, nurses, social workers, psychologists, recreation therapists, child life specialists, teachers and chaplains. The whole team has experience in caring for young people with cancer and their families. Medical center teams work closely with primary care doctors and others in the child's community to offer children the best quality of care.

Coping

Once a child is in treatment, parents must then find ways to cope with the needs of their sick child, maintaining their relationship and household, stay connected to their other children and manage the financial impact. All of those were difficult for Fraser, who spent weeks at a time in isolation with Lexi. Those long days often left her feeling alone. She took advantage of a supportive hospital social worker that not only provided the family with resources for practical and financial help, but also often lent Fraser an empathetic ear.

"I didn't realize how much Lexi would be hospitalized, and there were times that were very lonely and stressful for me. The social worker was great - she talked to me about anything I wanted to talk about."

The American Cancer Society encourages parents to be proactive in addressing all the emotional issues that arise as a result of their child's cancer, maintaining that knowledge and support are keys to coping. Some recommended ways to help families cope include:

- Learn all you can about your child’s diagnosis and treatment plan.
- Research progress in treatment methods.
- Give each family member a role in dealing with the illness. For instance, maybe someone keeps track of medical bills, organizes the cancer information you get, or keeps friends and family informed of what’s happening. Siblings and friends could be in charge of things like making cards or “goodie” boxes, recording favorite TV shows, or sending regular emails or texts.
- Keep a healthy balance between optimism and reality.
- Find support in prayer, religious faith or a spiritual outlook.
- Have confidence in your family’s ability to manage whatever must be faced.
- Share a sense of hope with one another.
- Develop trust in the skills of the doctors and other team members.
- Learn from the stories of others who have sustained hope in dealing with cancer.
- Find creative ways to bring joy or pleasure to each day.
- Learn to accept and tolerate the ebb and flow of hope.
- Appreciate the beauty and wonder present in life each day.
- Accept that we only have the present moment in which to live.

The [National Children’s Cancer Society](#) (NCCS) offers other tips in its free and printable parent guide called [The Other Side of the Mountain](#). Some suggestions it has found helpful to parents include:

- Give yourself permission to experience both positive and negative feelings and remember they are all normal.
- Understand that some questions may not have answers.
- Find ways to express your feelings.
- Take care of yourself: get sufficient sleep, eat properly, and exercise.
- Find a relaxing hobby like crocheting, knitting or woodworking.
- Spend time with your other children.
- Learn relaxation techniques, how to pace yourself and how to set priorities.
- Keep a journal and record special moments, both happy and sad.

Families receiving financial assistance from the NCCS are assigned a case manager who provides practical and emotional support to help parents be their child’s best advocate.

“We stay with them as long as they need us,” said Jessica Cook, program coordinator for patient and family services at the NCCS and a case manager for the past 15 years. That includes maintaining a relationship with the child even as they move into their young adult years.

For professional help coping with a child’s diagnosis and treatment, parents can get counseling referrals from the healthcare workers at their hospital or from organizations like the [National Association of Social Workers](#) and the [American Counseling Association](#).

Financial challenges

Financial issues quickly move to the forefront for pediatric cancer families, as costs quickly mount for hospital stays, clinic visits, expensive medicines, tests and procedures, surgeries, home health services and the fees of doctors and other medical professionals. Insurance, managed care or public healthcare programs pay many of these costs – but not all – if a child is covered under the family’s insurance plan.

Among families surveyed by the NCCS between 2011 and 2013, 96% reported that cancer put a financial strain on their family and 85% of families experienced a loss of income directly related to their child's illness. A larger study done by Dana-Farber/Boston Children's Cancer and Blood Disorders Center zeroed in on the economic impact that pediatric cancer treatment has on families. That study found that one-quarter of families of children being treated for cancer lost more than 40 percent of their total household income, while one-third experienced housing, energy or food insecurity.

Hospital social workers are a great first resource for parents, providing information on local and national sources for all types of financial help. Most hospitals have financial aid services, and Fraser encourages parents to apply even if they think they won't qualify. "It's surprising what they will do," she said.

Even when a family has insurance, there are many additional costs not covered such as those for travel, lodging and meals during treatments and hospitalizations away from home, extra childcare costs for siblings, special foods and nutritional supplements and equipment that might be needed. Nonprofit organizations like the NCCS are good sources for contributions to these types of non-medical expenses associated with having a child in treatment. The Ronald McDonald House Charities provide free housing near many children's cancer centers worldwide.

Additionally, there are organizations designed specifically to address the burden of health care costs such as [NeedyMeds](#). This nonprofit provides comprehensive and up-to-date information on patient assistance programs and other resources that can help families in need obtain medications and medical care. Another one is [Family Reach](#), which provides immediate assistance, education and outreach to qualified families, distributing millions in financial grants to directly help families in need.

Both the Thornocks and Frasers got much needed assistance from the NCCS with travel expenses, including hotel stays, gas, airfare and meals through the organization's Transportation Assistance Fund. The NCCS will also help families meet emergency needs such as mortgage, rent, utility payments, childcare, health insurance premiums, car expenses or treatment-related expenses. Parents can learn more about the organization's financial assistance and find an application [here](#).

The Frasers also applied for financial aid from their hospital, which reduced the amount of those medical bills. And they carefully budgeted financial gifts as well, including donations from members of their church, proceeds from T-shirts and lemonade stand sales held by friends, and a Go Fund Me page set up by Chris Fraser's coworkers.

"We also as a couple just had to communicate and budget together better," said Ashley Fraser. She said a financial class they had previously taken at church helped, along with asking the instructor for additional advice as they dealt with different financial challenges during Lexi's illness.

Adjusting After Treatment

The emotional and financial burdens don't end when a child finishes treatment and is deemed clear of their original cancer. This transition can be difficult as most children – like

Malcolm and Lexi – must get regular scans and tests for some time to come, continuing the upset to family life and ongoing medical bills.

It isn't easy, said Thornock. "We live life in three-month chunks. Malcolm gets his scans, they're clean, and we go home and try to live normally until the next ones."

For the Frasers, life after treatment has not only meant similar routine health tests for Lexi, who is now fearful of them, but also taking a slow path of letting her learn to play with other children again. Because she got so sick after every chemotherapy treatment, requiring ongoing hospitalization and weekly changing of her medication port, the once vibrant and carefree toddler eventually became anxious and non-trusting.

"She couldn't play while she was on chemo because she was so sick, and she eventually became really sad and withdrawn," said mom Ashley. "It broke my heart to see her change like that. But she has finally started coming out of her shell and has been playing well with her little brother. I would like to go back to work part-time, so I sent her to a couple of practice days at her daycare and she really enjoyed it."

Fraser is working with a new social worker to make sure she handles Lexi's emotions appropriately in light of the trauma she experienced as a young toddler enduring surgery and cancer treatment. "A temper tantrum is different for Lexi because she's been touched in ways she doesn't want to be touched and she's been through trauma. I want it to end right," she said.

For older children (10-17) who are going through treatment or returning to school after treatment, the NCCS offers a mentoring program that pairs them with a young adult cancer survivor. The mentors become a guide, trusted ally and caring role model in helping children face the challenges of childhood cancer and parents report that the mentors have made a huge difference in their child's ability to readjust after treatment.

Ultimately, a family's journey through pediatric cancer can not only bring it closer together, but also provide new connections that will remain for life. The Thornocks experienced this after putting their children in an annual summer camp – Malcolm for cancer patients and the other kids in one for siblings of a child with cancer. They've also connected closely to a group of students at Iowa State University who do huge annual Dance-A-Thons to raise money to fight childhood cancer.

"Our children have been deeply touched by the summer camp organization as well as the student at the university," said Thornock. "Both have been avenues to bring our kids in and show love and extra care for them." A great resource for families interested in camps for children with cancer and their siblings is the [Children's Oncology Camping Association, Inc.](#)

"We do everything we can for our kids, but it's clear they need extra support," said Thornock. "Our whole family has been blessed by connecting our lives with others. It's a lot easier for my wife and I to deal with insurance and treatment and side effects knowing that we're supported by all these other people."

About the NCCS

The mission of The National Children's Cancer Society (NCCS) is to provide emotional, financial and educational support to children with cancer, their families and survivors. To learn more about the NCCS and its support services, visit thenccs.org. To read all articles and white papers published by the NCCS, visit <https://thenccs.org/articles#>. The National Children's Cancer Society is a 501C(3) organization that has provided over \$62 million in direct financial assistance to more than 38,000 children with cancer. To contact the NCCS, call (314) 241-1600. You can also visit the NCCS on Facebook at <https://www.facebook.com/thenccs>.