

## [Psychosocial Challenges in Childhood Cancer](#)

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We're going to start with thinking about cancer as a chronic illness. Although it has acute phases to it, when they're diagnosed through the first six, nine, first year of treatment where they've seen a lot of hospitalizations, a lot of frequent clinic visits... We really have to look at it as a chronic illness because it lasts through treatment and beyond. And a chronic illness is really defined as something that lasts a year or longer, requires specialized treatments or technologies, and causes limitations in function, activities, social roles in the patients, as compared to their healthy peers. And that's really what I'm going to focus on today. As Ian and Dr. Dunsmore said, medical technologies have become more refined and effective for children with cancer. And a greater number of these children are surviving the diseases that may have once had a really grave prognosis. But with these survival rates, carry issues of adaptation, adjustment, coping, and a general emotional well-being.

The treatment, as Dr. Dunsmore and Ian also went over, it could include: surgery, chemotherapy, radiation, bone marrow or stem cell transplant. Or others, such as antibody therapies, that could last for years and years and years. And treatment is never a straight line. It would be nice if treatment went from A to Z. You were diagnosed, you took some medicine, you went to some doctors' appointments, you got done with treatment, and you went on with your life. But it doesn't happen that way. Life is not that easy and life with cancer is definitely not that easy.

We would love to have the child diagnosed and kind of go on a small roller coaster until they've completed their treatment and transition off treatment to their survivorship and on. If they could be diagnosed and just kind of have some small ups and downs... maybe a fever, maybe an infection. And they come off treatment, that's what we could hope for would be the best case scenario, but it never happens that way. But, it doesn't always happen that way. We have kids that are diagnosed and within the first month, they do not get into remission and have to go through induction treatment all over again. We have kids that are going along with treatment and relapse while they're on treatment, and go up here and have to go through intensive treatment again. And maybe even a bone marrow transplant. We have kids that are, obviously, at the end of treatment or have come off treatment. And then a few months later, relapse and have to start all over at the beginning again. And know we have some kids who just can't shake their disease and end up going on to palliative care and, ultimately, into grief and bereavement services that we offer as well. So, it is the worst roller coaster ride you could ever be on. It has the most loop de loops. It has the backward tunnels; the death drops... And just not a linear thing and with a lot of unpredictability.

So the psychosocial impact of childhood cancer... Again, previous speakers have talked about the physical, cognitive, vocational aspects of it. And I'm going to focus, kind of, on the other things that come along. Having a child with cancer, a lot of times we just think about it's the child with cancer. But really, that's the tip of the iceberg and you've got to look at the entire dynamic. The financial, the family, the social, and the emotional, and psychological because all of those go into treating a child with cancer. Such things as financial stability, family dynamics, social support, psychological well-being can be equally as important as the medical, physical, and cognitive equality of going through childhood cancer.

Financial. Not many think about the long-lasting financial impact that a diagnosis has on a family. And even the most financially stable family can feel the financial strain of cancer treatment. For leukemia, standard-risk leukemia, which is our most popular, most common illness that we see in our clinic. It's a

three-year treatment, from diagnosis to the end of treatment. That is three years' worth of treatment. The first six to nine months, the child is not able to go to school or daycare. And usually a parent has to stay home to take care of them, and therefore loses one income. And that's for a two-parent family. If you're a single mom, then you're losing your income altogether.

Most private insurances are going to cover about 80% of the total cost of the treatment, so the family would be responsible for the 20%. There are co-pays, and deductibles, and uncovered costs. The cost for leukemia, standard or low-risk leukemia, ranges anywhere from \$250,000 to a quarter of a million dollars. You throw in a bone marrow transplant; you are over a million dollars. So if the insurance pays 80% and the family's responsible for 20%, 20% of a million dollars is a heck of a lot for that family to have to be in charge of. And not all families will qualify for financial support from the government, such as SSI or Medicaid, as a secondary insurance. And there's also the money that's spent on meals at the hospital, gas to drive back and forth to the clinic appointments, to the hospitalizations, and to specialized therapies.

Say you live in Clifton Forge, which is where Alma's from, and you need to bring your child to treatment at Roanoke, Carilion Children's, and you need to be there twice a week. It's 50 miles one way. That's 100 miles round trip, or 200 miles per week, or 800 miles per month. That's the same distance as driving from Roanoke to New York, or to Atlanta, one time a month. That is a lot of gas. That is a lot of wear and tear on your car, and that is a lot of time that it takes to do that.

Family. We have to take into consideration that families come in all shapes and sizes. We have two-parent, intact families. We have divorced parents with joint custody who are fighting with each other. We have a widowed dad, raising two kids. We have grandparents raising grandkids. We have single mom with multiple children. We have kids in foster care and residential treatment facilities. Cancer does not care what kind of family you come from, or if you're financially stable, or if you have another kid with special needs, or if you're dealing with your own medical issues as well. It just doesn't care and everybody in the family is affected. We often say that childhood cancer is a family disease because no one in that family goes untouched by that illness.

It's especially hard on the siblings. Especially the siblings. Siblings may be shipped up to grandma's house while parents are in the hospital with the sick kid. Just yesterday, I was sitting with the parent of one of our patients. She is a 21-month-old who's in the hospital for five days for chemotherapy for a liver tumor. And she's got a six-year-old other child, a little boy, who was on spring break. The dad works construction. He's the only source of income, so he has to be at work. The little boy who was on spring break couldn't be at the hospital with the mom, so was shuffled to a different person every single day to help care for him. She has no family in the area. She has one sister. Two days he stayed with a friend of mom's who he had never met before. And the comment he made to mom was "You love the patient more than me because you never see me." They also feel left out. Siblings may not be included in family discussions. They may feel abandoned or isolated. Parents could be unwittingly doing this, or doing this in an attempt to shield that sibling, or they simply may not have the time or energy to spend with that sibling. And they feel cheated. Siblings often have to forgo their activities.

We recently had a sibling, it was a single mom with two kids. Both were school-age kids and the sibling had to give up their place on the soccer team because that single mom could not be at the clinic with the child getting the chemotherapy and being at the soccer practice with the other kid. So that sibling had to take a backseat. Siblings may feel cheated in both time and affection from their parents. And jealous. Children with cancer tend to get showered with gifts, and toys, and presents. Siblings can see

this and become jealous. They also can see that their ill sibling who doesn't have to go to school...sees this as kind of a perk. All the attention is on this sibling. Everything seems to be revolving around the sick child. And any one of these, or all of these issues, can cause the sibling to be depressed, or angry, or sad, confused, guilty, and act out. And a lot of times you guys will see this at school. Their behaviors are acting out. They might have had some psychosomatic issues where they're going to the school nurse because they're not feeling good because they just don't know how to handle their emotions. And their parents are having a difficult time sharing equal time with them. So please, please, please be aware if you have a sibling of a child who's undergoing cancer treatment, because they need special attention too.

Social. Socially, children going through treatment for cancer are greatly impacted. A child's job is to play and to go to school, both which are social activities, but kids with cancer are robbed of this opportunity. They're not in school. They have a lack of exposure to peer groups. They have a loss of contact with their friends. They have a loss of independence. They mature at a different rate and have a hard time reconnecting. They have feelings of being different and feelings of being left out. And for these kids, there's a whole range of emotion that they can experience. Most of them are intertwined and overlapping. They feel out of control and they have so many layers of loss. Loss of hair, loss of independence, loss of contact with their friends or their peers, loss of academic status or position on a team, loss of abilities, both physical and mental. They feel betrayed, unfairly singled out, angry, or embarrassed. And these emotions do not end at the end of treatment. They will stay with this child and the cancer survivor well after they have completed the treatment and have returned to school.

And the emotional scars. That's the best scar that I could get. We think of these invisible, or emotional scars, are the ones that you cannot see. Challenges with interpersonal peer and friend relationship is the number one issue that childhood cancer survivors say is their biggest concern. I'm going to say that again. Challenges with interpersonal peer and friend relationships is the number one issue that childhood cancer survivors say is their biggest concern.

I work, not only with the kids going through active treatment from the time of diagnosis to the end of treatment, but I'm also fortunate enough to be at our survivorship clinic on the one day a week that we have it. So I get to see the kids from the beginning of their treatment until they... forever. And the number one thing that they talk about, even though the cognitive disabilities that they might have, the chemo brain, the processing skills, the vocational challenges are all there and valid... The number one thing that they talk to myself and our psychologists about is their peer and friend relationships. How they just can't seem to feel like their peers and how they were.

They speak of not feeling like they can return to the way they were before. They see the world differently. They cannot connect to their peers. They have a different value. The things that they used to be engaged in seem petty and they struggle with feeling connected. These scars may be invisible, but real and cut deep. The child may physically look normal. Their hair is growing back. No physical limitations, like amputation. You can't see their port-a-cath scar. They're not taking any medications anymore. For all intents and purposes, they are back to normal, outwardly. But internally, they're far from normal. They feel different and they're struggling. And so be aware of this and be gentle with this. This is not something that they can get on with or will get over, but will need help finding their new emotional normal. A debate about using this analogy, but I'm going to go ahead... They remind me of peanut M&Ms. They are pretty and shiny, and bright-colored on the outside, but they are guarded with their protective coating. And on the inside, they have some vulnerability that is chocolate and sweet, but deep down, they are actually going nuts because they cannot find the way to be normal.

Balance. So we talked a little bit about the rigorous treatment for childhood cancer and the side effects, or late effects. And we've talked a little bit about the psychosocial issues that also can be present. So I want to put them together in a case example.

Sara. Sara's a teenager who resides with her mom, her dad, and siblings, who are 10, seven, and a new four-month-old. Mom just returned to her shift work at Wawa after her maternity leave, and dad works construction. The seven-year-old sibling has a significant learning disability and some behavioral issues for which he has an afterschool tutor and counselor. As a teen, Sara helps out a lot with the younger siblings and it's a role that she really takes a lot of pride in. The family only has one car, which dad uses for his construction job, and then they have to share it for mom's work and any appointments that they may have. And Sara's covered by Medicaid. Well Sara gets diagnosed with a brain tumor, and she's had surgery, and she was in the hospital for 12 days. Followed by that, she has six weeks of daily radiation. Every single day for six weeks. That's 30 visits. After her six weeks of daily radiation, she is seen once a week in the outpatient clinic. More if she needs a transfusion, or is ill, or has an infection. She's also admitted to the hospital for three days, once every 21 days. More if she has a side effect, fever, neutropenia, infection. She takes five pills three times a day. They make her nauseous, she is weak, she's lost weight, and eventually needs a G-tube for feeding. The feeds run eight hours a day, she's hooked up to a machine at home with TPN or Ensure running through it.

She's also scheduled for two days a week of physical therapy and occupational therapy because she's so deconditioned. And she's got one point a week for psychology counseling. That's four to five appointments just for the patient every week. The sibling has his own appointment for his tutoring and counselor for his learning disability and behavior problem. And remember, this is a family that only has one car that dad needs for work. Dad is struggling with some depression, and in the course of Sara's treatment, he is hospitalized for kidney stones. He has his own medical appointments, as well as his decrease in ability to work. We're now up to about seven to eight appointments a week for this family. We have lost an income. Dad has lost his income for reduced ability to work. And in addition to her physical and medical side effects, Sara's experienced some significant emotional issues, such as depression, low self-esteem, resistance to follow instructions. She's a teen, she's starting to act out, she doesn't want to take her medicine, she's becoming noncompliant, and she is very angry at the dependence that she has on the adults in her life because she physically can't get up and walk across the room to go to the bathroom by herself. She needs help by a walker or her mom to take her across the hall.

So looking at this schedule, how is she to keep up with school? How is she to keep up with her peer and social group? How are they going to pay the bills with mom not working and dad having to reduce his hours due to Sara's medical appointments, and his own medical appointments, and the brother's appointments. She was disconnected for an entire year during treatment, from her school and her peer group. And she had difficulty even participating in homebound instruction because she was so sick and she fell behind. She had difficulty participating in her physical therapy because she was so weak. When she was finished with all of her scheduled treatment, she was very, very far behind in school and out of touch of her peer group. She had long, lingering feelings of inadequacy, low self-esteem, and low stamina. She was easily irritated by things she used to find pleasure in, and could not find anything in common with her friends, and she just felt different from them.

So several years ago, we were able to put together a little video and this is the voice of the experts. I could sit up here and talk to you all days about my experience being a social worker and attempting or trying to walk alongside the journey with these children and their families. But as Juanita spoke so

eloquently this morning, I don't think there's any better educator than somebody who's actually walked through it.

[See [Dancing in the Rain: Life Lessons of Living with Childhood Cancer](#)]

We may not be able to fix all of the issues of a patient with cancer and their family. Nor is it our role to fix everything. But it is our responsibility not to break them further by ignoring the psychosocial, spiritual, academic, cognitive, and social aspects that the chronic illness creates.

There is no magic pill to give, or secret word to utter, that will make these emotional, or cognitive changes come about instantly. It took a while for these emotions and feelings to be created and reinforced. And it'll take a while to undo it and to find what is a new normal, so create a space of trust and safety. Allow the person to feel what they're feeling because these feelings are very real to that kid that's feeling them. Whether we think it's realistic or not. To tell them not to feel a certain way, that they shouldn't be upset, or they should be doing this is to disrupt the normal process working through these emotions. Telling them to get over it or that they're lucky that they survived is counterproductive and destructive.

Do not expect any child to return to the exact kid they were before treatment. And don't ignore the invisible emotional baggage and scars they are dealing with. And lastly, allowing a child who has gone through treatment for cancer, and who has lingering emotional and psychosocial challenges to struggle academically, socially, and emotionally when all that is needed for success is the appropriate awareness, accommodations, and interventions, is really no different than failing to provide a ramp for a child in a wheelchair. Thank you.