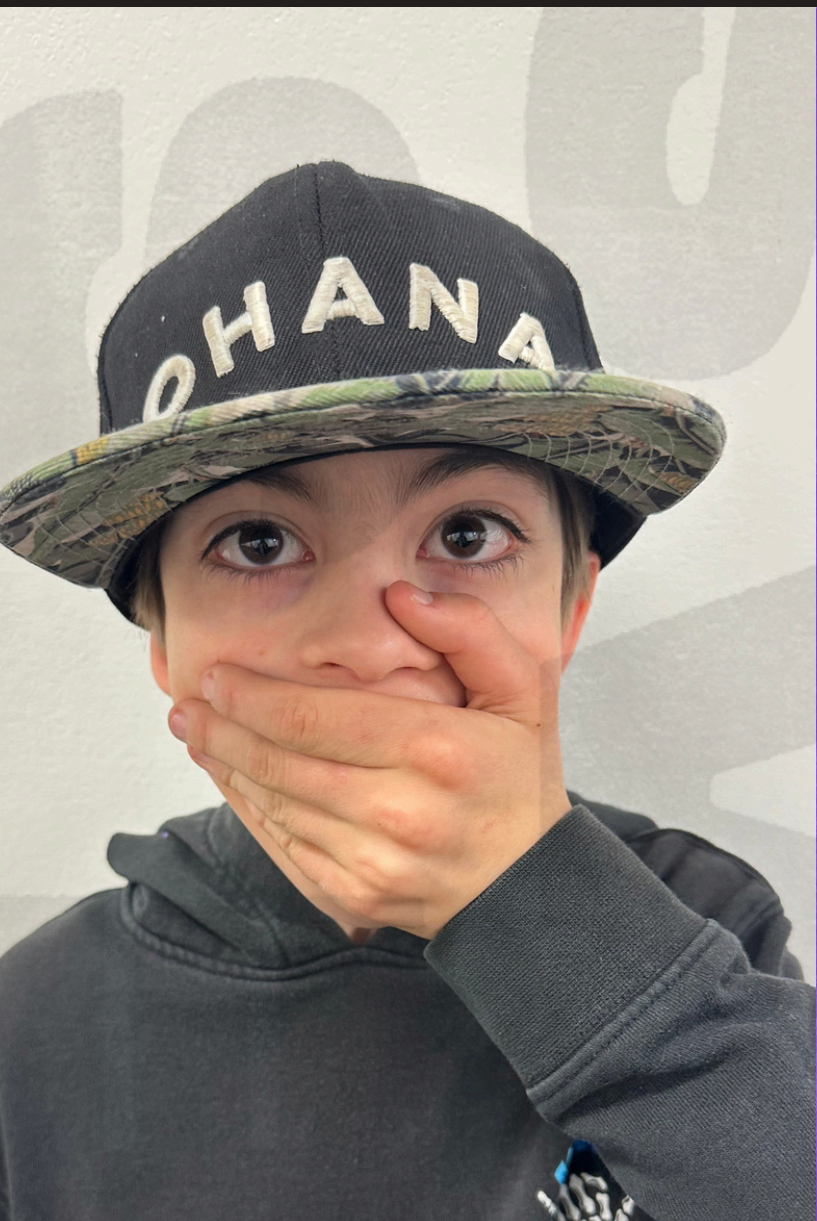


**WCK.**

**WEST COAST KIDS  
CANCER FOUNDATION**



**TALKING  
ABOUT  
CHILDHOOD  
CANCER.**



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# WHO WE ARE.

WCK

West Coast Kids Cancer Foundation (WCK) supports B.C. families with everyday things that make a big impact.



Our families need food, connection, resources, and mental health support while navigating childhood cancer and blood disorders. WCK walks alongside families with practical support that eases the burden.



# QUICK FACTS.

Around **350**  
can be on treatment at any time.

Childhood Cancer  
Family Support

Over **140**  
kids in B.C. are  
diagnosed with  
cancer  
every year.

BC Children's Hospital

**33%**  
of families navigate  
food, energy, or housing  
insecurity in the first six  
months after diagnosis.

Dana-Farber/Boston Children's  
Cancer and Blood Disorders Center

Complex blood  
disorders affect **100s**  
of children across B.C.

BC Children's Hospital

**Social isolation** is a common experience for families navigating childhood cancer and blood disorders. To feel alone at one of the hardest times in your life, when you need your community's support, can be distressing.

One reason for this is when the people around them don't know what to say, or are worried about being clumsy and "making it worse."

We've made this guide to help you overcome these worries and feel able to show up for anyone in your life who might find themselves on the childhood cancer journey.



# TESTIMONIALS FROM FAMILIES.

"Knowing there are people that care about supporting us... it feels like it's going to bring tears to my eyes. It's so loving to care about helping people in this way. It refreshes my sense of our collective humanity."



"Emotional support looks different for everyone. For me, it was as simple as a friend texting to check in. I didn't want to talk that much to be honest. I was focused on surviving and getting my family through."

"A quick text, call, or email to let us know you're thinking about us really means a lot. Please don't be offended if we don't answer."



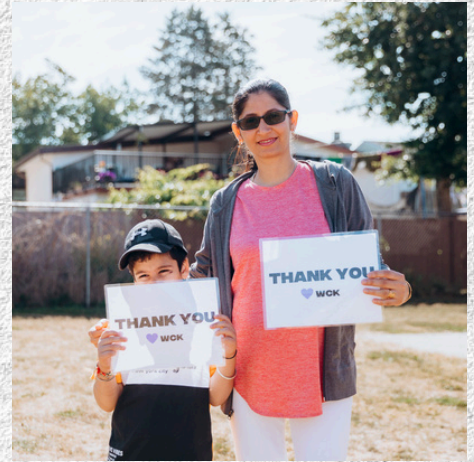
"When your child has cancer, it's normal to at times feel sad, scared, and hopeless. I need an emotional release so that I can stay mentally well."



**DESPITE IT ALL, IT'S MOMENTS OF LOVE AND  
SUPPORT THAT HAVE STUCK WITH ME THE MOST.**



# THANK YOU.



The fact that you're reading this guide means that you care, and that means a lot.

You won't always get it right, and that's ok. Psycho-oncologist Mindy Greenstein reminds us that "sometimes you'll do a 'don't,' no matter how hard you try. It's how we're built. I've said some doozies myself. Try to be yourself. You're our friend because we like each other, not because you can magically fix our problems. You help us just by being you."



# NOT JUST CANCER.

## **SOME KIDS HAVE COMPLEX BLOOD DISORDERS.**

Some blood disorders are classified as cancer, others aren't. Many families are treated on the same floor of BC Children's Hospital as children with a cancer diagnosis. Children can experience intensive treatments, symptoms, and side effects due to their blood disorder.

## **SOME KIDS HAVE SIMILAR TREATMENT, BUT NOT FOR CANCER.**

Conditions like Neurofibromatosis can cause significant symptoms, such as tumours, but are not always classified as cancer.

## **EVERY FAMILY DESERVES SUPPORT.**

Families can feel invisible when there's little awareness of the rare and complex diseases their children are facing. Every family deserves the resources and care they need to navigate their way forward.



**WE ADVOCATE FOR CANCER  
AWARENESS & SUPPORT.**

**WE ALSO ADVOCATE FOR FAMILIES  
NAVIGATING OTHER COMPLEX DISEASES.**

**ONCOLOGY, HEMATOLOGY, BMT... ALL  
ARE WELCOME AT WCK.**



# WHEN WE DON'T KNOW WHAT TO SAY.

No phrasebook exists that would work for everyone. Different people will always want to talk about their cancer experiences in different ways. For example, WCK avoids using words like “battle” and “fight” because we know many people are uncomfortable with the connotations. However, some families do choose those words because it fits their experience and perspective. We talk about cancer “journeys” but we know that this doesn’t feel right for everyone.

Let’s not let our fears about saying the wrong thing cut off our connection to those we care about. The Canadian Cancer Society has some tips from their online community about what can be helpful to say, but don’t worry if you feel clumsy. What matters most is that you care – communicating your love and desire to be there for them can be your focus.

**DON'T WORRY – IT'S NORMAL TO NOT KNOW WHAT TO SAY. GO WITH THE PERSON'S PREFERENCES AND LET THEM KNOW THEY CAN TELL YOU WHAT IS AND ISN'T HELPFUL.**



We want to **challenge the status quo** around how children and families with cancer and blood disorders are supported, and how we think & talk about them too.

**FOR EXAMPLE...**



## **WE SAY:**

children and families  
navigating childhood cancer

going through a childhood  
cancer journey

easing their way, knowing  
they aren't alone

connecting with others,  
accessing support

a warm and welcoming  
community

a place to express their full  
range of feelings

## **INSTEAD OF:**

childhood cancer victims or  
patients

coping with cancer or  
facing a life threatening  
illness

doing battle, struggling  
with cancer, fighting for  
recovery

being helpless

a safe haven

a place to always “stay  
positive”



# WHEN WE JUST CAN'T TALK ABOUT IT.

Apart from the weight of dealing with diagnosis and treatment, people find themselves constantly deciding who to tell, how much, how often, and how to deal with people's reactions. Having to repeat the news over and over can be upsetting too.

Talking – or not talking – about cancer is a deeply personal choice, and it's okay for someone to choose not to share. Some people, sometimes, know that not having to talk is exactly what they need.

On the other hand, maybe you are the one who doesn't feel able to talk about it. There can be so many reasons for this, and **if you can't be a go-to person for someone to talk to, that's ok.** It's good to be aware of what we can and can't be for other people, and there are different ways to show up and show our care.

Chopping up a supply of fresh veggies is just as valuable as being a listening ear. Providing car rides to appointments, getting siblings to soccer practice, and buying travel-sized toys for hospital stays can all show your care beyond the expression of words.



**IF THEY DON'T WANT TO TALK ABOUT IT, THAT'S OK. IF YOU JUST CAN'T TALK ABOUT IT, THAT'S OK TOO. SUPPORT TAKES MANY FORMS.**



# WHEN WE FEEL THE FEAR.



No doubt about it. Studies show that we tend to fear cancer more than any other serious illness. When someone in our world is affected, our own fears can increase.

Sometimes it feels like thinking and talking about it makes it more real. It's like when people don't want to make a will because they feel like thinking about death makes it more likely to happen.

As scary as it is to think about, it can be much more heightened for families who spend years in "cancerland." They're not only on their own journeys but they also form deep and close relationships with other families going through treatment. When you're in the eye of the storm, it can feel like cancer is everywhere. By providing a listening ear, maybe some of us can help to ease that burden.

In a culture where people don't want to think about children having cancer, it can take time to get used to talking about it. It might never feel "comfortable," because it's not a comfortable thing. But the more we get used to talking about it, the less power the word "cancer" has over us.

**BE REASSURED — TALKING ABOUT CANCER DOESN'T MAKE YOU GET CANCER. KNOWING SOMEONE WITH CANCER DOESN'T MAKE YOU GET CANCER.**



# WHEN WE DON'T HAVE ANSWERS.

We've got some good news for you on this one. You don't need to have any of the answers, and nobody expects them from you.

We've heard from different family members about advice they've been given over the years about supplements, diets, asking whether their sibling stood too close to the microwave... and none of it helped.

Families facing childhood cancer don't need answers from you, and they will let you know if they want advice. What they *do* want is to know that you care.

You can find out what support looks like to them and show up in those ways.



**YOU DO NOT HAVE THE ANSWERS, AND THAT IS OK.**



# WHEN IT FEELS TOO BIG.

Mark Story writes about how cancer presents a big communication challenge, because it doesn't fit neatly into sound bites. That's even more true with childhood cancer. It's a complex world of confusing medical and scientific language, deeply emotional and nuanced experiences, and the constant intrusion of fear. No-one could ever encompass the entirety of someone's lived experience and all the ways that childhood cancer impacts every aspect of their life.

But perhaps that's not what's needed. Instead, we can focus on being present, learning from the moments we get a glimpse of, and sharing ideas that help supportive people to know how they can show up. We are just one part of a whole – what a difference a community can make when each person does a little bit.



← In community,  
each person can hold a piece

**WE WILL NEVER FULLY KNOW SOMEONE ELSE'S CANCER EXPERIENCE,  
BUT WE CAN LEARN WAYS TO WALK ALONGSIDE THEM.**



# WHEN WE CAN'T FIX IT.



This is perhaps the most painful reason that cancer is hard to talk about: Nothing we say can make it better for a family. And it's what we desperately want to be able to do. But while we don't have the power to fix the situation, the good news is that letting someone talk with us does help. **Research** shows that talking can release emotional pain. By providing space for someone to talk about what they're going through, we can provide them with some relief.

People often say they felt "lighter" after talking about it, or "I just needed to get it off my chest." Talking to someone who listens and acknowledges your experience is powerful and eases the burden.

**LISTENING DOESN'T MAGICALLY MAKE EVERYTHING BETTER, BUT IT CAN PROVIDE MUCH-NEEDED RELIEF.**



# TALKING WITH KIDS.



If you're looking to talk with children about cancer, here are some great online resources:

## **FOR KIDS WITH CANCER**

[Canadian Cancer Society: Talking to your child about their cancer](#)

[Imaginary Friend Society](#)

## **FOR KIDS WHO KNOW SOMEONE WITH CANCER**

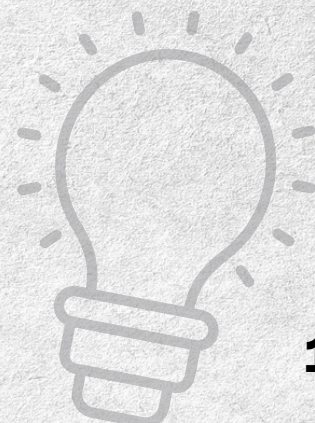
[BC Cancer: Children & teens](#)

[Alex's Lemonade Stand: How to talk to kids about cancer](#)

## **EDUCATION ABOUT CANCER**

[Imaginary Friend Society: What is cancer?](#)

[World Child Cancer: What is childhood cancer?](#)





# READY TO HELP?



## WEST COAST KIDS CANCER FOUNDATION

Registered Charity #721885291RR0001

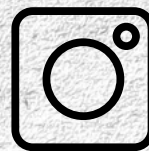
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