

# What NOT to Say to a Pediatric Oncology Family

When a family receives a childhood cancer diagnosis, it's natural to want to do something or say something.

## **Unfortunately, there are no magical words.**

What needs to be heard is a very personal thing to each person and family. Knowing the right thing to say (and what not to say) can sometimes feel impossible.

Below are a few guideposts for navigating the topic of pediatric cancer with oncology families. Although missteps are a part of being human (and we've all put our foot in our mouth), we hope this will be a way we can lighten the emotional load for oncology families.

### **1. "Tell me everything that's going on" – Sometimes staying quiet is okay**

Take the caregivers lead. If they want to talk about it, let them. If they do not, don't. Try to "read the room" and go with their flow. They may have talked to many others before you and may not want to go over every detail a seventh time that day. Or, they just might.

**Examples:** *Embrace the silence and just be.*

### **2. "You're so strong – you'll get through this!" – Avoid toxic positivity**

Dr. Jaime Zuckerman describes toxic positivity as "the assumption, either by one's self or others, that despite a person's emotional pain or difficult situation, they should only have a positive mindset or 'positive vibes'". This messaging has a way of creating shame and guilt while simultaneously dismissing their experience, feelings and thoughts.

**Examples:** *"You're so strong" | You'll get through this. | Your strength is amazing. | Everything happens for a reason." | "Everything will be fine because the prognosis is good." | "It is what it is." | "You have 2 other children so you should feel blessed." | "You're okay"*

### **3. "Everything happens for a reason" – Avoid the positive spin**

These pop up in comparative statements and sometimes carry a spiritual tone. Again, read the room – not every positive quote on Instagram is helpful.

**Examples:** *"At least they got the good cancer." | "God doesn't give you more than you can handle." | "Everything happens for a reason." | "Heaven needs children, too." | "At least their cancer is curable." | "They are in a better place now."*

### **4. "I was reading on Google/Facebook that..." – Avoid unsolicited advice**

Don't comment or inquire about treatment in front of the child unless the parent initiates. Don't ask how they could possibly give their child chemo when there are natural treatments available. Don't ask questions for your own curiosity or to reiterate your personal beliefs. If families want to talk about treatment options, they will bring it up. If the person making the recommendation is not their primary oncologist, they do not want to hear unsolicited advice.

**Examples:** *"Someone did \_\_\_\_\_ treatment and their cancer was cured."*



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## 5. “Will their hair fall out?” –

### **Don't ask questions to satisfy your curiosity**

It's natural to be curious and want to ask questions. But for those living through trauma and hardship, questions can sometimes be perceived as intrusive, nosy and potentially triggering. Let the parent initiate what and how much they want to share - they may open the door easily.

**Examples:** “Will they be better after treatment?” “So, after a bone marrow transplant he will be totally fine?” “What are you going to do when their hair falls out?” “Are they cured now?”

## 6. “I know exactly how you feel” –

### **Not every experience is a “shared experience”**

A desire to create connection is natural but it can sometimes result in anger, frustration and isolation – as though the person speaking couldn't possibly understand what they were feeling because they said something so disconnected. This could include venting about how tired and exhausted they (non-oncology family) are or comparing the loss of a pet to the loss of a child.

In bereavement, there is nothing similar to losing a child. Even losing a loved one like a parent or a spouse is still a different type of grief.

**Examples:** *I know exactly how you feel.* | *I remember when I lost my grandparent...* |

## 7. “How did they get cancer?” -

Do not inquire, under any circumstance, about the cause of the cancer.

The causes of pediatric cancer are primarily unknown and unrelated to lifestyle and environmental risk factors. Suggesting otherwise is unnecessarily painful to families.

**Examples:** “How did your kid get cancer?” | “Do you think it was something you ate or suffered while your child was in utero?” |

“Were they fed organic food?” | “Were they formula-fed or breast-fed?” | “Was there anything you could have done to prevent this?” | “Do you think they got cancer because they eat sugar?” | “Was this cancer from your side of the family or your husband's?”

## 8. “They're in a better place now” -

### **Don't say silly things (& no, “silly” was not the first word that came mind)**

One parent revealed how comparison made her feel: “Don't compare my kid to another kid you know who had this cancer and beat it. Don't tell me that if my kid is strong and fights hard, they will beat cancer. My kid is strong and will fight hard, but he has no control over the outcome of his treatments.”

Also, don't tell a parent that someone they know passed away from the same cancer (and especially in front of the child) or that once treatment is over they can get back to a normal life.

**Examples:** “You're young and can totally have more kids.” | “They are in a better place now.” “I'd come visit but I just don't think I can see your child so sick.”

