

Behind This Face Shield, I See You

Jori F. Bogetz, MD

Dear Mother,

I know you have been in this fight for over a year now. You tell me it has been longer than you expected, as most of the other families you know whose children have the same tumor have already died. You tell me you are one of the lucky ones.

Only a small fraction of your beautiful child remains. In the hospital bed, she is unable to move much anymore and can only share a few mumbled words at a time. I see her curly locks of hair growing back after surgery and radiation—fresh and light like the very young child that she is. “Her hair was gorgeous before,” you tell me. It must be utterly, totally, and completely devastating.

And yet, you do what you must. You are there for every sip of juice she gestures for and every time she needs you to gently stroke her forehead in reassurance. You are there when she needs your help to change positions and to change her diaper. You are there when she has pain in the middle of the night and after she wakes from what seems like endless days of somnolence. You are calm, methodical, a hero playing a role you never wanted. I see you standing on the edge of the abyss.

With me, you keep it to the facts. We talk about hospice and what home might be like—the reasons why your oncology team asked me to meet you. Your other healthy child pulls at your shirt from the shelter of your lap. He’s an infant and he needs you too. You tell me you want to be in the hospital for the extra support, the additional hands, the knowledge about what happens while your child is dying. But coronavirus is frightening you and changing your calculus. Your reasons for being at the hospital during your child’s final days seem obsolete and unobtainable. You don’t say why, but I know it is because the medical world outside your child’s room is spinning. You tell me you just want more time with your daughter and to keep her comfortable. You think your family might be safer at home. I can see in your eyes that you are worried you can’t do it all alone, but who could?

You cannot see me behind my face shield, mask, gown, and gloves. You only see another person coming into the room suited like an alien from Mars. I have come to talk with you about things you do not have the energy to discuss or even fathom. I know it feels like I don’t speak your language, like I don’t understand. I know it feels like I’m distant, like we can’t connect. I feel it too.

There are no hugs right now, no way for you to see the gentle smiles of understanding under what’s covering my face. You feel isolated and contaminated, when in fact I’m the one isolated for fear of contaminating you. I am sorry I can’t support you the way I want to. I’m so sorry.

I can see as I leave that you still feel alone. In a glass container, fending for both of your children on your own. There is nowhere for sanctuary—not this hospital room, not home, not anywhere. The tumor and the virus have made sure of that. Through this sterility, I know you can’t see me witnessing your strength, offering you reassurance that you’ll make the right decision, and wishing you peace. I have tried and failed. When your child is dying it takes more than words alone. I know that. I wish I could show you that behind this face shield, I see you.

Sincerely,

Your Pediatric Palliative Care Doctor

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