

## Bling

By Samuel LeBaron

At our weekly pediatric hospice team meeting, Carol told us, “Divya is deteriorating, but her mother still refuses to give her morphine.”

The medulloblastoma had invaded the girl’s brain so intimately that surgery and radiation therapy were of no use; chemotherapy was no longer effective; so her parents were told to give her all the pain medication she needed to control her headaches. The plan was “comfort care only.”

Carol described how she had tried every persuasive argument she could think of, but the Divya’s father, who worked as an auto mechanic, deferred to his wife. Divya’s mother was adamant that she wasn’t going to make her daughter become a “narcotic addict.” Carol had tried to tactfully remind Divya’s mother that her daughter was close to death. Her brain tumor was causing frequent headache, nausea, dizziness, intermittent vomiting, and weakness in her right arm and leg. Divya spent most of the time in bed, eyes closed, and begged her parents for her anything that would help relieve her suffering. Her mother refused, believing that narcotics would cause her to become addicted and shorten her life.

“Doctor, you’re good with children and parents,” Carol said. “Maybe you could make a home visit and convince the mother.”

*Namaste.* Divya’s mother greeted us with hands together in the hallway of their small apartment as Carol introduced me. She showed us into their dark living room and invited us to sit. The only light came through a gap in the curtains and from a lamp in the corner. A hospital bed in the center and a table crowded with medication bottles and some small statues dominated the room. Divya lay on her back, eyes closed. I sat on a sofa a few feet away while Carol checked her blood pressure, pulse, and temperature; then she checked the medication bottles. Divya’s mother sat in a corner behind me.

“You haven’t used any of the pain medication,” Carol whispered to the mother.

Mother closed her eyes and held up one hand. “No, she didn’t need it.”

Carol glanced at me as if to say, “You see?”

Divya opened her eyes and looked at Carol, then at me.

“Hello, honey,” Carol said. “How are you doing?”

Divya didn’t answer.

“Having any pain right now?”

Divya whispered so I could barely hear. “Head. Bad headache. Neck. Back pain.”

Carol sighed. Then she turned toward me. “Divya, this is our doctor. He wanted to meet you and your mother.” She turned to Divya’s mother. “And your husband’s at work, right?”

Divya glanced toward me, rolled toward the edge of the bed, and struggled to sit up. Her mother rushed over to the bedside to help. She and Carol supported Divya as she walked slowly toward the sofa, where she sat down beside me. Divya’s face and body looked bloated from the steroids she took every day to control the swelling in her brain.

I stood up and asked her mother if I could talk with her while Carol visited with Divya. She seemed surprised and a little nervous, but she agreed, and we sat together in the kitchen. "Is there anything I can do to help you?" I asked.

Her eyes filled immediately with tears. "No doctor, nobody can help. My husband's family, his brother and sister and his mother, they come over every Sunday. All they do is criticize me. They say it's my fault she's not getting better."

"Why your fault?"

"Because they said we should take her to this ayurvedic doctor in India, he gives people some special treatments, and they said he can cure her. But I told them no, if his treatment is better than the doctors here, then everyone with a brain tumor would go to see him, because everybody would be cured. But that's ridiculous, so they became angry with me and they told my husband to take her anyway. He told them he doesn't want to be involved. He just stays at work, and that means they come now and tell me it's my fault." She stopped to wipe her eyes.

"What do you need?"

"I need them to go away. I need my daughter to get better and go back to school and be a happy girl again."

"You know she's not going to get better."

"Yes." She nodded her head and covered her face with a towel.

"She's dying, gradually."

"Yes. I know."

"But she's still alive, she's here with us. And we can still take care of her."

"Yes. But I don't know how. I don't know what I can do to take care of her. Sometimes I think they're right, it's my fault."

"It's not your fault. None of it."

She looked at me.

I added, "It's an accident of nature when some abnormal cells grow in the body."

"What can I do with his family?"

"Are they his family only?"

"Yes. All of my family is in India."

"Does your husband agree with them?"

"No. He said I should tell them to go away. Stop coming over to bother us. I told him, 'No, you should tell them.' But he's afraid. That's why he goes to work every day."

"Do you want to tell them to stop coming?"

"Yes, I do. But I guess I'm afraid of them too."

"You could tell them they're welcome if they come with food, love and support. But not if they come with criticism. Your life is hard enough already."

"Yes," she said, and wiped her face. "I would want to tell them that." Her voice sounded strong and determined.

"It's okay to feel angry," I told her.

"I know. I get angry with my husband but really I'm angry at them." She sighed.

"This may be one of the most difficult things of your life. But you can do it, for Divya's sake and for yours."

"Yes, you're right. I was trained to be obedient. But I know you're right. That has to change."

"Do you want me or Carol to come to a family meeting to give you support?"

She studied my face. "No doctor. That's so kind of you. No, you're right, I must face this. Just to talk with you, I know I have your support. Thanks doctor."

“Good for you,” I said. “Now to focus on Divya, how do you want the rest of her life to be?” She looked at me, puzzled. “What I mean is, in the remaining days she’s here, you’ll have to choose sometimes between keeping her comfortable or keeping her awake.”

She took a deep breath. “Of course. I want her last days to be as comfortable as possible, and she should...” She had to pause and collect her breath. “...She should pass away peacefully, comfortable, when it’s time.”

“The most important thing for her will be to have you and her father close by. Next most important will be to decrease her pain so she doesn’t suffer.”

“I know. Carol told me. I should give her morphine.”

“It’s your choice. It’s for Divya’s comfort, and to make any little moments of time when you’re together have as little suffering and pain as possible.”

“I understand, doctor. You’re right. I’m so afraid.”

“We’ll help you.”

“Thank you, doctor.”

“Thanks for your courage.”

Her eyes filled with tears again and she bowed her head.

“Here,” her mother told Divya. “I have some pain medication for you.” She showed Carol the dropper of sublingual morphine. “Do I have the right dose?”

“Yes, good. What you have here is a perfect starting dose. But remember, the right dose is what she needs to control her pain. So, you’ll need to adjust up or down.”

Divya opened her mouth and her mother placed four drops under her tongue. Her mother replaced the dropper then bent over and kissed her daughter on her head. Then she sat down next to her, their bodies touching.

I sat in a chair across from the sofa where I could see them both. Divya made shy glances at me, while she played with a gold bracelet on her wrist.

“Nice bracelet,” I said.

She smiled and extended her wrist toward me.

“You like jewelry?” I asked.

She nodded her head. “I have a lot more.”

“Really? I’d love to see it.”

She pushed herself up and gradually stood, swaying, then turned and shuffled toward a bedroom door. Her mother gasped, extended an arm to steady her, but Divya said, “It’s okay Mom. I’ll be alright.”

The three of us sat nervously, almost expecting to hear her fall to the floor in the bedroom. Instead, after a moment, she reappeared with her hands full of costume jewelry: bracelets, necklaces, rings, balls, hoops, miniature animals and earrings of all types. She plopped down on the sofa with her shiny handful and smiled at me.

I pulled my chair next to her and leaned forward. “It’s beautiful,” I whispered. “Would you put some of them on?”

She began to load her arms, wrists, fingers and neck with the golden beads, links, chains, circles, stars, of all kinds.

“You call it ‘bling?’” I asked.

She laughed. “See Mom, I told you. See, the doctor said it’s ‘bling.’ Didn’t I tell you?” She turned to me and Carol. “She thought it was a bad word.”

Her mother looked embarrassed, but she smiled.

“Mom takes me over to this store—it’s just over there in the mall—whenever I’m feeling better, and she lets me buy whatever I like.”

“Ahh,” Carol said. “What a great mom.”

“Yes, she is,” said Divya. She leaned toward her mom and whispered, “I have to lie down now.”

When Divya died three weeks later, Carol was there. At our team meeting, she told us that she and the other nurses checked on them two and three times every 24 hours during the last week. Divya was almost always asleep, mostly comfortable. During her last moments, the parents scattered Divya’s pieces of jewelry all over her body and the blanket.

“Like stars in the sky,” her mother told Carol.

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**Samuel LeBaron was born in Canada and completed his medical school training there. He earned a PhD in clinical psychology from Michigan State University. Now living in California, he is a Stanford Professor Emeritus with a long career as a family physician and clinical psychologist. His career has included research on management of pain in children and adolescents in cancer; primary care for children and adults; adult and pediatric hospice; and active engagement in medical education. Although he has published extensively in academic journals regarding pain and dying among children as well as adults, he has only recently turned to creative writing. He recently completed a memoir, “Ordinary Deaths.” In his experience, our stories make us more mindful and appreciative of ourselves and others.**

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