A serious illness is hard on any family, and it can be particularly challenging when there are children.

Our pal Joey

Anne Riffenburgh, LCSW

I heard the Regas family before I saw them. As the murmur of voices drifted out of the radiation oncology treatment room, one voice in particular caught my ear. It was high and childlike but surprisingly direct and self-assured. Setting aside my charting, I peeked through the doorway.

Jay, one of the technicians, stood next to our top-of-the-line radiation delivery system and fielded questions from a family of three. Dad sat in a wheelchair with ramrod-straight posture that hinted at a military background. He was a burly guy, but it was clear from his hollowed-out cheeks that he'd lost weight recently. The right side of his head was shaved and bore a clean white bandage. Mom stood nearby, one hand resting lightly on her husband's shoulder. She was pretty, with a gentle gaze, but dark circles revealed her fatigue. The third member of the family was a boy about 9 years of age who combined the liquid eyes of his mother with the husky build of his father. His was the voice that I'd heard, and the questions were still coming, in rapid succession:

"How does that machine work?"

"How do you make sure the radiation beam goes to the right place?"

"How do you make sure that my dad doesn't get too much radiation?"

"Is the radiation going to zap the leftover cells from my dad's brain tumor?"

"Is it going to make him feel sick?"

These sophisticated questions mirrored many of the same concerns raised by adult patients and their loved ones when radiation treatment is about to begin. Jay patiently answered each question, and the family relaxed visibly. As they left the room, I intercepted them and introduced myself as the social worker. The boy paused in his efforts to navigate his dad's wheelchair, and I smiled at him. "I see you're being a big helper today."

That was all it took.

"My name's Joey, and I love my dad so-o-o-o much. Sometimes I ask a question, and I don't get an answer, so I decided to come with my mom and dad and see what was going on. I said to myself, 'Why not?'"

"And are you getting your questions answered?"

"Oh, yes," he said, nodding his head so vigorously that a lock of dark hair fell over one eye, giving him the rakish look of a young pirate. "Yes, I'm very satisfied."

The Regas family was doing all the right things to help Joey adjust to his father's illness and understand the treatment regimen. They had created a safe environment where he could ask questions and express his concerns. They offered straightforward explanations. When they couldn't answer questions to his satisfaction, they brought him to the medical professionals who could. Our doctors, nurses, and radiation technicians treated him with the same level of respect they would show to any family member. The whole family benefited from open and honest communication and a sense that they were all in this together. Joey was allowed to take on certain tasks—pushing the wheelchair and bringing his dad a glass of water—that served as tangible expressions of his love and desire to help.

A serious illness is hard on any family, and it can be particularly challenging when there are children. The following tips may be useful to share with parents to assist them with helping their children understand and cope with the disease:

- Provide short and simple explanations
- Ask your child if his or her questions are being answered
- Let your child explain the situation to you so that you may offer clarification or correct any misinformation
- Reassure your child that the illness is not his or her fault (Children are egocentric and may believe that they somehow caused the illness or are being punished.)
- Be aware that some regression is normal; for example, your child may return to such behaviors as thumb sucking or bed wetting
- Maintain routines to foster stability
- Give hugs
- Find age-appropriate tasks that allow your child to be helpful and participatory
- Let your child's school know that your family is coping with a stressful medical situation
- Seek professional assistance should your child display prolonged distress or behavioral problems.

Joey pushed the wheelchair into the room where the CT scanner was housed, and a technician named Frank helped Mr. Regas to his feet. The last thing I heard before the door closed behind them was the sweet, probing sound of Joey's voice: "But why did they name that machine for a cat? And how does it take a picture of my dad's brain?"

Mr. Regas successfully completed 6 weeks of radiation treatment for an aggressive glioblastoma. The last time I checked, he was doing well. He had regained some strength and was out of the wheelchair and using a walker to get around. Surgery and radiation were undoubtedly crucial factors in arresting his disease, but he will tell you that the best medicine has been his family—especially a little boy named Joey who loves him so-o-o-o much. And here in the radiation oncology department, we are very satisfied with that. ■

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