

# THE LEFT ATRIUM

## Room for a view

### The last day

*In the pediatric intensive care unit, the difficult decision to forgo life-sustaining treatment must sometimes be made. The ICU doctors, the social worker, pastoral care, RTs ... they all come and go into the room. However, one staff person — a nurse — is left to be with the family at all times, on the last day of their child's life.*

**N**ursing a child through the end-of-life process is really very individualized and yet has elements of similarity. My personal philosophy is to treat every family and every child as if they were my own. My main objective is for the family to remember these last few moments with their child as peaceful and filled with love, kindness and nurturing. For the most part, I have had the time and opportunity to develop a trusting relationship with chronically ill patients and their families before the withdrawal of life-sustaining treatments.

Patient care is very “hands on” and I endeavour to have parents participate in care, to whatever level is comfortable for them. Losing control of care is a major cause of stress for parents, who until then had dedicated themselves to caring for their child. Mothers often want to wash their child's face and hands. This is usually when I bring the quilt that we provide as part of our bereavement package and explain that their child needs something soft with colour to keep them warm. Often parents will apologize for being in my way while I work. I make every effort to explain that their job is to hold their child's hand and to love them and that anything I have to do can be done around them.

Parents often want to talk about their child and tell me funny anecdotes. I al-



Daniel Garros

ways make sure that I maintain eye contact and let them know that whatever they have to say, someone is listening. Parents will ask if I have children and I always tell them a little bit about my own boys. We talk about children in general, their hopes, dreams, likes and dislikes. We talk about things that never change about children, like when you hold your child and smell their hair ... it is just like when you held them for the first time as newborns. There is something about that smell that never changes. Parents will often hold their child's blanket or pyjamas to smell their child.

Sometimes the room can be filled with family members. I try to ask the person who has taken the lead role how they want to manage the numerous

guests. I explain that I can limit visitors and that I can be the person who imposes limitations if this is more comfortable for them. I let them know that if at any given moment they just want some time alone with their child, all they have to do is give me a sign and I can make an excuse to have the room emptied for a period of time. I also let them know that I understand that family is important and that I will not adhere to the “2 people at the bedside rule” that we usually have in the ICU. I explain that in the case of an emergency in the unit I may have to ask the family to leave. As a general rule, however, parents can have as many guests as they want, and as much love as they need to be surrounded by. This is fine with me!

At some point in the day, usually as early as possible while still maintaining sensitivity, I ask if the family would like me to contact pastoral care or their own family religious leader. Throughout the day, I try to find the right moment to ask if the family would like handprints, hair clippings, etc. Some families want pictures taken. I do my best to accommodate their wishes. I bring them juice and glasses of water into the room. Many parents do not leave the unit for any reason, so I just like to ensure that they at least have something to drink.

If the child is small enough, I put them in their parents' arms for as long as they wish, after getting the go-ahead from the attending physician. If the child is too big or unable to be held, I try to make room in the bed for the parents to lie down beside their child one last time. I remove unnecessary equipment from the room to accommodate guests, to give parents a place to lie down even for a brief moment and to make the room appear *less hospital-like*. When the time comes to actually withdraw life-sustaining treatments by stopping inotropes and extubation, the family has already asked and I have explained exactly what will take place. The primary concerns are usually, "Will my child suffer?" "How long will it take?" "How do you know my child is not in pain?" "Are you sure nothing else can be done?" "Have we made the right decision?" "How will you know when they are gone?" Prior to extubation, I turn off the monitor and silence all of the alarms. I remain in the room in a corner or just outside. Throughout the day I try to provide moments of privacy to the family and try to be as unobtrusive as possible, yet I let them know I am there if they should need me in any way.

At the end, when the child has died, I always ask the parents if they want to bathe their child and put clean pyjamas on. Seldom has a parent remained to do this. Most parents ask me to "please take care" of their child. I promise that I will stay with their child as long as I can and this seems to be what parents want to know. They don't want their child to be alone. Parents will ask where their child will go after I have bathed them. I explain that they will be taken to the morgue, but I will make sure that they are in new pyjamas and

wrapped in their blanket. This is when I give the family the bereavement package and tell them that they can call anytime in the future. The bereavement group then receives the information about the child's death, a personal card is left in the ICU for all of the staff to sign and the follow-up is scheduled.

This last day is over.

## Book review

### The limits of hope

#### The road

Cormac McCarthy

Random House; 2006

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We all, someday, are going to die. About this fact "there is no manner of doubt, no possible probable shadow of doubt, no possible doubt whatever" (W.S. Gilbert, *The Gondoliers*). So too, it seems obvious, some day, all human life on earth will end. And be it 5 hundred million or a billion years from now all life on earth will draw to a close when our sun goes Nova. While it is easy, and perhaps comforting, to imagine life on earth continuing long after our species is departed, in *The road* McCarthy imagines a brilliant reversal of this.

In the near future, an unnamed catastrophe has enveloped the earth. The sky is permanently darkened, the ground coated with soot and dust, fields covered with crumbling stocks of grass and ashen vegetation, and *Homo sapiens* is the last remaining species to walk the earth. The few survivors live off what they can salvage from the rotting stinking ruins, and they live off each other. In this nightmare of darkness, soot, ash and cold, McCarthy has inserted a boy, called simply "the boy," and his father, known throughout as "the man." They wander down a road toward the Pacific coast, travelling through the remains of the past in search of a future that no longer exists. The child is perhaps 6 to 8 years of age; we know only that he was born shortly after the end of the world.

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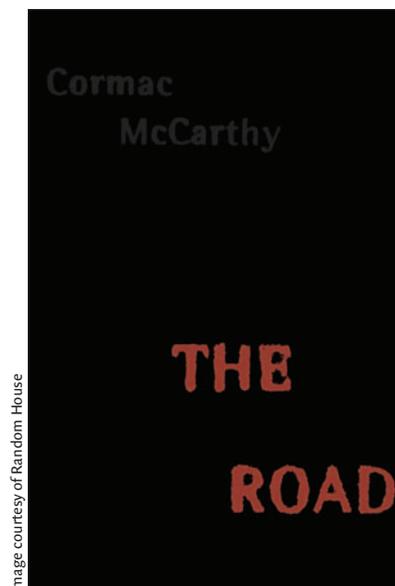


Image courtesy of Random House

In embarking upon the journey to the coast, a transitional boundary of symbolic importance, the father is maintaining hope and a belief for the future for himself and his son. By virtue of not eating other survivors they are the "good guys, the keepers of the flame." When they see another child in the ruins the boy wants to care for him, to let him come along on their journey. "I saw a boy," he says. "We should help him."

They move on; logistics demand that they leave the desolate child to his fate.

I needed to read this novel twice, as it kept exceeding my capacity and endurance; some sections compelled me to skip over details and paragraphs. In one section I overlooked, as did the man, the vital clues McCarthy lays out for us, resulting in a horrifying and jointly unexpected discovery. The climax of the book occurs shortly after this scene; the father must leave his son alone for several hours hidden in a field. Before he leaves he attempts to ensure that his son can kill himself with the last remaining bullet, if