

## Room for a view

## The doctor's doctor

"But was she limp?" the pediatric gastroenterologist said over the phone. I couldn't answer. For the second time in my life, I was speechless. I knew she had turned blue. I knew she had become bradycardic. I could describe every detail of her silent, terrified face as my baby had vomited, choked and aspirated for the third time that day. But I couldn't remember whether she had become limp. Some doctor.

The specialist didn't know our history. He didn't know about the emotional roller coaster we'd been on for the past 115 days with our twins in the neonatal intensive care unit. He didn't know what it was like not to be allowed to hold your child until 58 days after she was born. He didn't know how inadequate it made you feel to have your baby taken from you, reintubated and resuscitated next to you because she was too unstable to be held skin to skin.

Really, all I wanted was for him to tell me that these episodes wouldn't mentally or physically scar my baby. I wanted to be told she wouldn't die. Sleeping or waking, I had visions of finding her dead in her crib, blue. So I didn't leave her with anyone. Every night for the next two years she slept elevated on a pillow next to me. Whether I would have been able to save her from a fatal aspiration, I will never know. Would I do things the same way again? Yes.

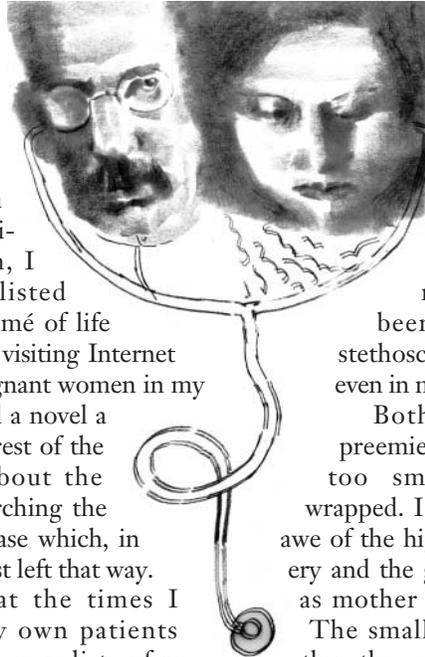
My journey into the inner echelons of the health care system began when I was first told about the intrauterine growth restriction developing in one of my monochorionic twins. After we met with the geneticist, the second obstetrical radiologist, the nurse clinician and the third perinatologist, the situation was still unclear. As a physician, I had read and could quote many recent articles on possible diagnoses. I had even gone so far as to phone various specialists who had published in this area.

None of this did anything to relieve the anxiety of waiting. My husband and I trudged through the remaining

months of my pregnancy with home and hospital bedrest. I was not an ideal patient. Accustomed to the lifestyle of a rural general physician and surgeon, I wouldn't have listed bedrest in my résumé of life skills. I resorted to visiting Internet chat rooms for pregnant women in my predicament. I read a novel a day and spent the rest of the time worrying about the what-ifs and researching the unknowns of my case which, in retrospect, were best left that way.

I laugh now at the times I cringed when my own patients would bring their own lists of resources and questions regarding their illness. They would present their diagnoses and possible treatment options. I would quote clinical practice guidelines at them and say, "This is the standard treatment for this illness." Now I understand the importance of participating in one's own care.

The first time I was ever rendered speechless was when I saw my 560-gram and 910-gram twins. I had no professional experience in a neonatal intensive care unit, and hence no mental image that might have prepared me for its emotional paradox. They wheeled me on my stretcher from the recovery room into neonatal intensive care, whose alarms, lights and machines over rows of incubators resembled a highly perfected assembly line of humans. This looked nothing like the natural parent-child relationship I had seen in family practice. I could remember my own obstetrical patients saying, "Don't cut the cord until it stops pulsating," or "I don't want my baby to have any needles," or "Do you have to put the drops in his eyes?" Such concerns seemed like irrelevant details to me now.



Nothing could have prepared me for seeing my own babies in these incubators. Nothing in medical school or residency had prepared me for this doctor-patient experience. I wish I had

been able to leave my stethoscope at the door — or even in my pocket.

Both twins lay on their preemie diapers, as they were too small to have them wrapped. I was torn between my awe of the highly technical machinery and the grief of losing my role as mother in this environment.

The smallest twin was shorter than the unwrapped diaper. Only small areas of skin were visible through tapes, tubes, lines and sensors.

"She is beautiful," the nurse said, but my first remark was, "She looks like a chimpanzee." From my stretcher, I was able to reach through the porthole of the incubator and briefly touch the foot of the larger twin. I convinced myself that they were real and that they were mine. My first words still echoing in my head, I was wheeled back to my hospital room. There, I spent the first of many sleepless nights to come.

The stage was set for the next four months: pumping breast milk every three hours, daily visits, living away from home, learning to hold and care for a preemie as a parent, and a more detailed look into the health care system as a doctor-patient.

The last part got me into trouble. My suggestions on ventilator settings were met with great opposition by most of the staff. I insisted on knowing test results and detailed information regarding treatment plans. This often made the team uncomfortable. "You be the patient. We'll call you if there's a problem." But I couldn't stick to my

role. When the team worked well together, communicated test results and treatment plans, I was a “good” patient. When there were weak links, I stepped in, as I did in my rural practice, to fill the gaps. Sometimes this was a conscious decision. Sometimes not. Either way, for each of those 115 days, I muddled through the dual role of doctor–patient.

It was not a role I perfected. Take,

for example, the sunny Saturday morning in December, when my husband had gone home to our community for a few days to work and check on our house. Fifty-eight days had passed since the twins were born. It was 10 am, later than my usual visiting time because I had stayed with the smallest twin until one in the morning. She had been very unstable. I started the routine; I washed my hands, asked the front desk if it was okay

to visit the girls, put the pumped and labelled breast milk in the refrigerator and made my way to their place in the line of incubators. I glanced around the unit to see if there were any new arrivals to the nursery. I thought of how lucky we were to be almost 60 days into the journey and not at the beginning. I silently laughed at the thoughts I had entertained a couple of months before: “We won’t be here that long. My babies will be different.” Now I wondered whether I would have the strength to keep going.

As I strolled toward our corner of the intensive care unit I saw the neonatologist running toward me. What could be so urgent? The last time he ran was to tell me that the lung of my second twin had collapsed and that she was on 80% oxygen. A composed wave of detachment came over me; as someone who sometimes had to deliver devastating news, I was trained to shield myself from emotion.

I didn’t hear the first part of the neonatologist’s conversation. I was waiting for phrases like “passed away” or “unlikely to survive.” But when “CPAP” and “well” penetrated my protective shield, my senses awoke just enough to decipher that my littlest twin had been extubated and was on another trial of continuous positive airway pressure.

For the rest of the day and most of the night, I sat outside her incubator, hoping for a miracle that didn’t happen. It would be another three weeks before she was successfully extubated and I heard her cry for the first time.

Now that I see my girls running around, doing somersaults and discussing whether they want scones or cookies at their pretend tea party, I can begin to let go of the intense helplessness that has been with me for so long. I can let people with a cold come to the house without worrying that this infection might make them ill again, or lead to another hospital admission. I can separate the roles of physician, mother and patient.

Sometimes.

**Nancy Humber**  
General Practitioner – Surgeon  
Lillooet, BC

Past progressive

48 [Canad. M. A. J. Aug. 1948, vol. 59]

**"one nervous woman**  
... can give rise  
to more diverse, undiagnosed  
and undiagnosable complaints  
than a whole pathological ward."

*Harding, T.S.: M. Rec. 160:198 (April) 1947.*

**Eskaphen B Elixir**

provides—in delightfully palatable liquid form—both the calming action of phenobarbital and the tone-restoring effect of thiamine.

*For the nervous patient with poor appetite*

*Smith Kline & French Inter-American Corporation, Philadelphia and Montreal*

*Canadian Distributors:*  
*The Leeming Miles Co., Ltd., Montreal*

Advertisement from the August 1948 issue of CMAJ.