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INSIDE AN ICU
A MOTHER'S BEDSIDE VIGIL

BY DAPHNE LARKIN

October 7, 1986

Lucien turned five years old today but he doesn't know it. At 6:30 this morning they rolled him to the operating room so the doctors could slide a scope down his throat into his lungs to view the problems there. For the past four weeks, since Labor Day when we brought him to the hospital for what was intended to be an overnight stay and checkup, Lucien has been hooked up to a machine that helps him breathe.

This is the lowest ebb since he underwent open-heart surgery nine months ago. We had high hopes then that surgery would correct the birth defect in his heart. But things did not go well. We nearly lost him. He "recovered," but now his heart disease is complicated by a paralyzed right diaphragm and damage to his right lung.

The right lung complications put him at great risk for the procedure he is undergoing at this moment. The doctor who is performing the examination told us yesterday, "I'd sleep better tonight if I knew I didn't have to come here tomorrow and do this. He may die on the operating table, he may die within a month as a result, or he may survive."

Once again Lucien's father and I have had to talk about the possibility of his dying. We discussed how we would cremate his tiny body and scatter the ashes some 3,000 miles away in a remote forest surrounding a lake in the Adirondack Mountains. That is where his grandmother's house is. The place where he used to drive the outboard motorboat, catch baby fish, hike the piney trails, and walk on the ice with his new Christmas skis. It was there that he most wanted to go when his bright light was fading.

Later the same morning

The procedure went without a hitch! And the news is good. The lungs apparently are not damaged beyond repair. His father, his grandfather (who sat with us for the past two days), and I leave for lunch while Lucien sleeps off the sedation. We are renewed.

October 16, 1986

Here I sit by Lucien's bedside watching him nod in and out of a morphine sleep. The pain of yesterday's surgery on his diaphragm is just beginning for him, for us. It will be months before his chest muscles—which were sliced through—are free of the hurt. We wait to know if his right lung will ever expand again, if he will get well. We pray that this surgery will help him breathe on his own, without the aid of a ventilator.

October 17, 1986

A young Indian girl stares out from her enclosed chamber. "How is Lucien doing?" she asks. Her name is Prabha and her concern for him is touching. She looks as if she's survived a terrible fire—her beautiful dark skin is peeling in layers, her hairless scalp is tattered by strips of skin that will soon fall off—but actually she's been ravaged by chemotherapy and has undergone a successful bone marrow transplant.

"I don't think I could put my child through that," a nurse confides to me. "How painful is it?" I ask. "Agonizing," she replies.

Prabha's mother steps out of the sterile room where her 14-year-old girl has been for weeks now. Prabha's transplant is taking, she whispers happily, removing her sterile gown and mask. The tortured expression she wore on her face during those dark days of fear of losing her daughter has vanished.

It's Sunday and Prabha's family, Sikhs who emigrated from northern India, have come from hundreds of miles away for the day. The festive Punjabi dress worn by the women and the delightful aroma of curry momentarily sweep this sad room into another world.

October 18, 1986

Lucien dozes in and out of a troubled sleep. They are reducing the morphine now, three days after surgery. I have to give everything I have to him now. It's Zen-like, totally focusing on this one thing, directing all my energy to helping my son get well. Our doctor believes that Lucien may be in the ICU for months. We've been through this once before, after the open-heart surgery. Can we possibly do it again? When I am exhausted, I think I can't. But I know I must. I will.

October 20, 1986

Lucien desires nothing new—just comfort. He doesn't want his Snoopy dogs. He shakes his head listlessly when I ask him if he'd like to listen to his favorite tapes of Raffi, James Taylor, Bruce Springsteen. I rocked him this afternoon for over an hour; he just sits limply in my lap. His father shows him a picture of the Golden Gate Bridge, explains that home is on the other side, and reminds him how we'll be driving that way soon. Lucien listens attentively. I see hope in his eyes.

October 28, 1986

Lucien's spirits are improved. It's nearly killed us, staying here day and night, but we've been doing it now for weeks. Lucien seems to accept that we can't continue to, however.

"It's going to be a long haul," our doctor tells us today. I am certain of one thing, though: Lucien will get off of these machines. It may take a year, but I envision him running around again unencumbered. His father now carries him and his Snoopy dogs to a window so he can see the Golden Gate Bridge. They both point to it. Lucien later

listens to Bruce Springsteen's "Born in the USA" for the first time since his operation.

November 1, 1986

Four-month-old Johnny is still here. I didn't think he'd make it through the night. When I left yesterday, this baby boy, who has never breathed on his own, was dark purple. His malformed heart was failing.

Today, he's less purple and his dad tells me he's doing better. To my eyes, it doesn't seem possible. He is the size of a newborn. His skin is rough and patchy. He lies there unmoving. Usually, the only thing that makes me certain Johnny is part of the human race is his eyes. Today they're closed.

November 11, 1986

Seven-year-old Katie's mom trembles. Her dad smiles strangely and won't talk. Their hope seems gone. They've just learned their daughter has brain tumors. Meanwhile, Katie, who looks as robust as any second grader, has lost a tooth and eagerly awaits the arrival of the tooth fairy. I want to help, but don't know how. I take Katie's mom out for coffee. She sobs between sips. I am crying, too.

November 18, 1986

I ponder Lucien's future. Mine. His father's. His little sister Zoë's. We are inextricably linked together. Like a train gone off the tracks. I worry for all of us. It's two-and-a-half months that Lucien has been living in the ICU. Living with terrible pain and fear and hope. These are long and anxious days. There is no pleasure now. We are stuck in a kind of tortured limbo. Lucien's father—torn between the demands of his new job and the needs of a critically ill son—despairs. He works, he comes to the hospital, he sleeps in a chair by Lucien's bed or on a mattress in an adjacent room with the other frightened parents. And Zoë. My darling two-year-old. She seems lost and I am unable to help her now.

November 20, 1986

I am watching Lucien's nurse try to place an IV line in the three-month-old baby next to us. She's been digging around with the needle for 45 minutes now. The baby writhes in pain. His cries cannot be heard because he is attached to a respirator. The nurse is having no luck, but she continues. She might as well be washing dishes for all the empathy she's showing. I cannot watch. I want to scream at her to stop.

November 26, 1986

We are mobile now! Lucien is being weaned off the ventilator onto a specially designed mobile oxygen unit. He has to breathe more for himself now. This system is on wheels, and it is almost as good as a tricycle! Lucien and I and the Snoopys can get out of the ICU briefly. We go up to the nursery to admire the newborn babies. The doctors are encouraged. Plans are being made to send Lucien to the regular ward. Thank God. The ICU has been an extremely difficult place for our family—most of all for Lucien.

December 1, 1986

We rolled a smiling Lucien, a Snoopy dog under each arm, down to the regular ward this morning. What a difference! Our own room! No bright lights. No noise. No beeping monitors. No ringing alarms. And a bed for me in Lucien's room. The nursing staff listens to my concerns. They respect my knowledge of Lucien's condition. I feel as though we're halfway home.

December 6, 1986

Baby Johnny died this morning during open-heart surgery. His family's five-month vigil, always so bleak, is finally over.

December 10, 1986

Lucien breathes on his own, with the help of extra oxygen through a tube. We wait anxiously for signs of difficulty. None yet. Everyone is smiling today.

December 12, 1986

Progress continues. The last oxygen machine is wheeled out of the room. Lucien waves good-bye to it and so do his Snoopys. It's a victory for all of us. Mostly Lucien. There is talk of home. Home? I can barely believe it.

December 16, 1986

It's nine days till Christmas and we're going home. We just crossed the Golden Gate; Springsteen is blasting from the cassette deck. Lucien is frail and sickly, but his spirits soar. And so do ours. □

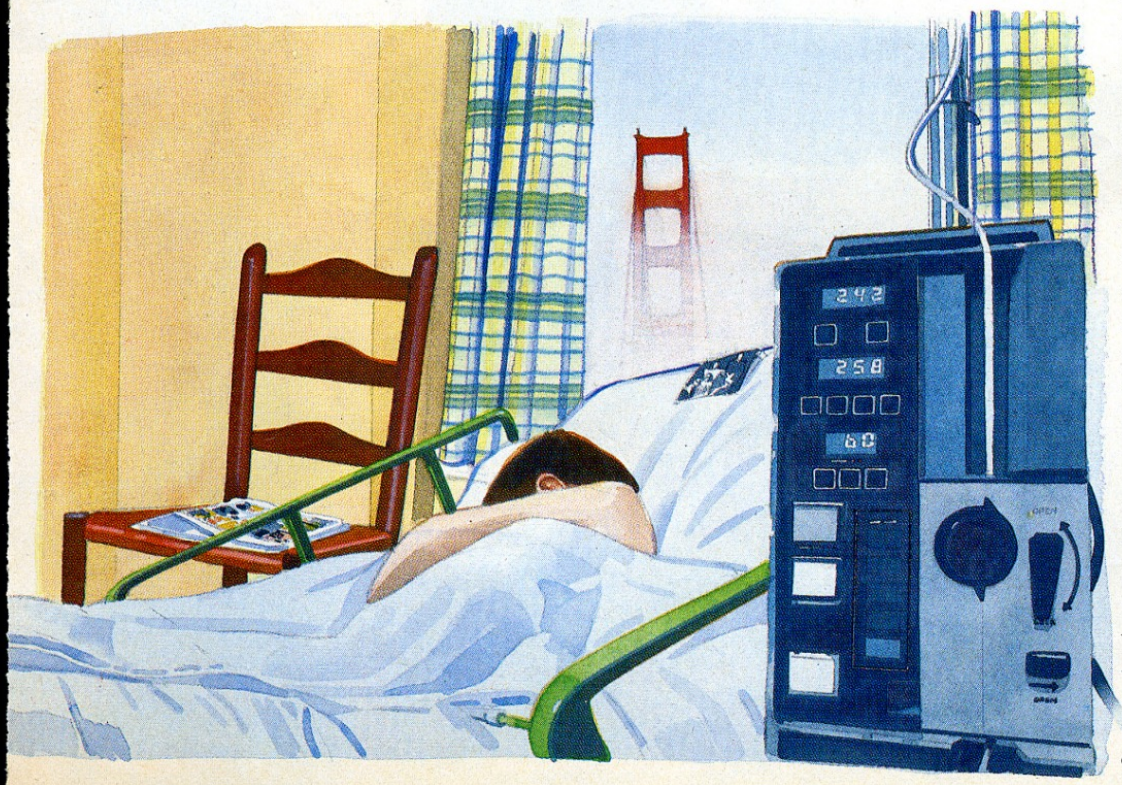

ILLUSTRATION JULIAN ALLEN

Daphne Larkin is a freelance writer living in Corte Madera, California. She is writing a book about her family's ICU ordeal.

INSIDE AN ICU WHAT EVERY PARENT SHOULD KNOW

Chances are you will never have to see the inside of a neonatal or pediatric intensive care unit (ICU). But if your child should require such life-saving measures, it is best to be forearmed with some essential strategies to help reduce the inevitable stresses of the ordeal.

Maintain control: Don't abdicate your role as parent. This may sound simple, but it's not. When your child is under the hospital's care, your parental role changes; studies show that this is traumatic for parents, but some of the stress can be alleviated by participating in your child's care as much as possible. Some of the hospital staff may oppose your efforts, but don't let yourself be intimidated. Instead, be sympathetic to their concerns without sacrificing your own.

Be there: Obviously, you cannot be with your child all of the time—you'll have to take occasional breaks for some much-needed rest. But try to leave only when your child is feeling secure and be sure to tell him when you will return. Nighttime is often the scariest time for young children, and exhausted parents should ask relatives and others close to the child to share the "night shift" duty.

Stay informed: Ask questions. Ask the nurses, ask the specialists (cardiologists, anesthesiologists, surgeons), ask the physicians in charge of the day-to-day running of the ICU. Ask them anything and everything: What's the diagnosis? What tests and procedures are required? Why are they needed? Can the information be obtained in any other, less stressful way? Is such information really necessary? What medications are being prescribed? Are there any side effects? Is there an alternative treatment? Remember, you have a right to a second opinion; if you have any doubts about your child's treatment, ask for one.

Insist on one nurse: If your child has to stay in the ICU for more than a few days, ask to have a primary nurse assigned to oversee his care whenever on duty. Such a person can become a great support and advocate for both you and your child and can relay your concerns to other medical personnel.

Be open: If your child is old enough to talk, speak openly to him about his illness. What you say and how you say it will vary greatly depending on the child's age. Do not, however, let your child hear every negative thing there is to know about his condition. Hold conversations with nurses and doctors away from the bedside.

Stand by: Stay with your child during any painful procedures. Routine tests and injections are often the most terrifying aspect of a child's stay. If a nurse tells you to leave, firmly stand your ground and speak to the doctor in charge. Your comforting presence can make all the difference to your child. Also, have it written in red on his chart, and reiterate to the staff, that you want to be present for any procedure involving a needle, unless, of course, it's an emergency. Needles are extremely frightening to a child. Request that they be kept out of sight until ready for use; anticipation can be worse than the jab itself.

Let them sleep: The effects of sleeplessness are a serious problem in ICUs. Ask that your child not be awakened unless absolutely necessary. Often, routine temperature and blood-pressure checks can wait until after a much-needed nap. Bathing, weighing, and sheet changing can be done during the day rather than late at night. Offer to help if the nurse is busy.

Get physical: The emotional and physical reassurance of your embrace is the best weapon against a child's despair. Ask for a rocking chair, pillow, blanket, or anything else you might need to hold and comfort your child. If you can't pick him up, caress and cuddle him frequently.

Bring toys and books: Also, give him a cassette player and make tapes of his favorite stories and songs. It will be comforting for him to hear your voice when you're not there.

Prevent slipups: Watchful parents can prevent things such as duplicate X rays, the insertion of an IV line when the decision already has been made to forgo it, blood drawn twice when once would have sufficed, laxatives continued even though yesterday's constipation is today's diarrhea—the list is endless, and the chances for less-than-optimal care are abundant.

Fixing the hurt: Many doctors, believing that infants and children do not feel pain as intensely as adults do, won't prescribe enough painkillers following surgery. Small children, particularly nonverbal ones, may have trouble describing their pain. Nevertheless, a child's behavior is a reliable indicator. Consistent crying, irritability, or facial contortions should not be ignored; stronger medication may be necessary.

Visitation rights: A visit from a brother or sister can boost a sick child's morale. But before bringing other children to the hospital, prepare them for what they will see. Until recently, siblings traditionally were not allowed to visit ICUs. However, the benefit to the hospitalized child is now regarded as so significant that the American Academy of Pediatrics recommends liberal visiting policies.

Join a support group: Parent support groups usually meet weekly in the hospital and give parents a chance to share their concerns and voice their complaints about nurses, doctors, and hospital administrators. There is both solace and strength to be found there.

Organ donation: A child's only hope for life may depend on organ transplantation—and that child may be your own. The time to think about becoming a donor or making your child a donor is when you and your children are healthy. Livers, hearts, kidneys, and other organs and tissues are gifts of life to children—and adults—who need them. For further information concerning transplants or donor agencies, phone the American Council on Transplantation in Alexandria, Virginia, at (703) 836-4301. —*Daphne Larkin*

Left: Kevin O'Donnell, recovering from reconstructive surgery on his esophagus, watches TV with a familiar friend. Below: In order to hold the intravenous tube in a child's arm, nurses wrap the insertion area with tape and gauze and bind the child's arm with a splint. Intravenous insertion, blood drawing, and other procedures performed with needles are among the most painful and disturbing treatments young ICU patients undergo.