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Early

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It is always better to be early they say. Definitely better than being late, particularly as a young trainee in medicine – a field filled with rounds, teaching, more rounds, clinics, and very patient patients who always seem to be waiting.

But sometimes it's better to be just on time. Or even a bit late.

Pediatrics is a unique field in medicine, because generally speaking, most of our patients are in good health. Those who are not often have the opportunity to manifest the resilience characteristic of a young mind and body.

Newborns who enter the world earlier than expected are a bit different. Landon was. His parents, as accomplished as they were optimistic, viewed his birth after just 27 weeks in the womb as a sign he was a “go-getter.” Landon had clearly become bored of the mundane intrauterine environment and was ready to take on the world as soon as he had the ability to do so.

And he surprised all of us. Though the delivery was complicated, and he was initially dis-

tressed, he quickly became “vigorous” – a term we use favourably in newborns, as it refers to an infant’s ability to transition well to a world outside the uterus. For very preterm infants, it is a challenge to facilitate things that are normally completed in utero – their continued growth and development – within the walls of a hospital. But, we try our best, and many of these infants go on to live normal lives. Landon was expected to be one of them – and at three pounds two ounces he surely showed us the “right” signs.

Shortly after he was born, Landon had an ultrasound of his head that showed moderate bleeding into his underdeveloped brain tissue. “Moderate” is better than “severe” – in medicine, precise terms are often coupled with statistics that attempt to help both the physician and patient distinguish between hope and naivete. His chest X-ray showed lungs that were very small and underdeveloped, preventing him from breathing on his own, but allowing him to live with the assistance of a complex ventilator. His heart, perhaps the source of his resilience, was okay. Indeed, we were optimistic.

Once Landon reached 43-hours of age things changed.

The first time you see a silent cry – the expression of discomfort without an audible sound - you never forget it. When even the slightest touch on a premature infants’ tissue-paper skin is met with an inaudible scream, powerful even against the noisy milieu of cardiorespiratory monitors, you start to wonder where to draw the fragile line between healing and harming your patient. When the thin

tube that provides minute amounts of infant formula starts to show flecks of blood from stomach irritation, you start rethinking how basic human needs can be met without causing further damage. When obtaining bloodwork is met with jerking of limbs that barely measure the length of your fingers, you realize that being early can be very a difficult thing.

Landon's parents, at the bedside since his birth, often asked different members of the care team about whether we were closer to sending him home. His mother even kept a carseat near his isolette. It was a gift from a baby shower the week prior to his birth and seemed to serve as a reminder that Landon has a home that had been waiting for him for 27-weeks. Sometimes it is helpful to focus on what we know in medicine. It somehow seems to dwarf the vast amount of uncertainty we face everyday. We knew he was gaining weight, and his heart and kidneys were functioning relatively normally.

Indeed in medicine, when the idea of losing hope is unpalatable, one can choose to stick to "objective" facts, at least until new facts scream back at you.

Over the next few days, Landon's silent screams and restlessness became more frequent and less responsive to pain-relieving medication. His second head ultrasound now showed a "severe" bleed in his brain, into areas responsible for movement, but also cognition and basic functioning. His lungs continued to become more ineffective, requiring even more oxygen, which at high levels can be damaging to other organs. Then his

heart started to show us signs that it was exhausted. He was becoming less resilient in a world that only days ago seemed to be on his side.

Once ahead of the pack, early and eager, Landon was starting to lose the race, and someone had to say it.

The first time you hear a parent cry about their child, you never forget it. They were unprepared for Landon's early arrival, but optimistic. Now things had changed. We assured them that though his arrival was hurried, they had time and our support to process everything we discussed and could think carefully about what they felt would be best for Landon.

They decided to use Landon's own cues to guide their decisions. During bloodwork his heart would beat much faster, he would arch his tiny back, and appear to cry without tears. We stopped the bloodwork. His ventilator was one that required him to be sedated, restricting his purposeful movements. We switched to a more basic ventilator. Efforts to wean his pain-relieving medications were met with further agitation. We kept him comfortable with a combination of two different medications at a dose that worked for him.

One morning my fellow trainees and I received an email that we would be meeting earlier than usual for rounds. That was the morning the silent screams stopped. The noisy monitors had become quiet. Both hope and naivete that Landon had improved clinically flashed ever so briefly through my mind before leaving it blank. Overnight he had pulled out his breathing tube, I was told, and his

parents decided they just wanted to see his tiny face, without tubes and lines. His eyes were closed gently. I'd like to say he had a calm smile across his face. The truth is that his isolette was dark and he was bundled in such a way that I could barely make out his other features. My attending explained that Landon had passed away a few hours earlier. The attending wanted us to experience and understand the decisions and tribulations of letting go of a very sick preterm newborn, the cognitive dissonance between the excitement of bringing a new life into the world and the realization that that life could be inexplicably fragile and short. By arriving early that day we were able to share that time with Landon and his family.

We are taught that medicine is not an exact science, but the pure science of it is actually quite well delineated and easy to master with time and diligence. I think the art of balancing the emotions and ethics of providing good medical care, while respecting the values and integrity of the family and patient is the imprecise part.

During his short life Landon helped shed light on this balance, one that is hard to teach even for the most experienced medical attending. At the end of rounds that day I finally understood that Landon was not early at all. He had arrived just on time.

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