

Lessons from Luna

Annabelle Hughes
Griffith University
Brisbane

In the special care nursery lie 12 tiny, vulnerable newborns – born too early or with complications, and all requiring full time care. But only 11 families come to visit. One tiny baby lies in the corner of the room – sleeping, swaddled, and alone.

The morning ward round comes to a stop around her crib and the team of doctors and students crowd around her. It's a striking visual, several adults craned around this tiny fragile baby. Luna doesn't stir. I scan my eyes over the paperwork lying on the bench beside her and linger over the words 'query neglect'. As her story is told, it feels as though she's shrinking, becoming even more fragile, right in front of us.

Luna was born more than 10 weeks prematurely. The ambulance had picked her up from a 'crack house' as documented in the notes. Her mother was using drugs throughout the pregnancy, both parents 'blazed' at the time of Luna's delivery. Not a single family member has come to see her, now a month since her arrival at hospital. Family have been contacted, times scheduled for a visit, but time and time again, nobody shows.

A medical overview is tossed around verbally between doctors. It is a waiting game they say, she needs weight gain through her nasogastric tube, eventual oral food tolerance, respiratory monitoring and caffeine for her regular apnoeic spells. But despite the daunting medical milestones she must yet reach, there is much more concerning social component – where is her family? Every day that she waits for somebody to show is another day without the necessary physical and verbal contact that a baby needs for development. Nurses provide daily monitoring, bathing and feeding, but time constraints prevent the nursing staff from being able to give her the nourishing attention she needs. The consultant explains how the absence of being held or spoken to, and the deprivation of maternal contact in particular, will adversely affect Luna's cognitive, behavioural and speech development. I felt my understanding of her situation shifting; Luna was not merely unfortunate for not having visitors, she was being disadvantaged. Luna pulls a face and stretches her tiny, almost translucent hand. It was as though her little hand was pulling invisible strings and tugging at my heart. This poor little darling, oblivious as she was to her rough start in the world, was falling victim to neglect in a room full of people.

While I was busy contemplating the injustice this little baby had already stacked up in her short lifetime, the ward round had moved on and we left Luna. But Luna did not leave me. I thought about her for the rest of the day. I felt an ache to go back and pick her up, to hold her against me and protect her from the unfair lack of affection she was suffering. I replayed the morning ward round in my mind. It felt sterile and unnatural to walk past, none of us having touched or spoken softly to her despite acknowledging

how that was what she needed most. 'I have two arms' I thought to myself, and I could fix this baby's current state of deprivation.

Being Luna's visitor became my new mission. It wasn't long before I became friendly with the nursing staff and with the families that were also frequent special care visitors. My name was even written on her medical records as Luna's official 'cuddle carer'. I fed, bathed and changed her. I would put her against my chest so she could feel my heart beat and feel close to someone that cared about her. I exhausted my repertoire of lullabies, singing and humming to her. I would chat to her non-stop to squeeze as much verbal stimuli as possible into the few hours I spent with her per day. I read her storybooks and I would tell her about my day. I whispered to her about how precious and important she was. I told her that even though her family didn't come, it was no reflection of her own worth. She was loved, and I adored visiting her. I told her she would grow to be big and strong, and that despite her rough beginning, she would flourish. I would read aloud from the study books open on my lap while I nursed her in my arms.

Nearly every day I would come to visit Luna, and I became so fond of that time together. Before or after a hospital shift, or even during my lunch break, I would come to see her. Sometimes I would come to hospital especially to visit her, weekends in particular, not liking to think of her lying there alone for extended periods of time. I looked forward to seeing her, I thought about her when I was away from hospital, and I took great personal interest in her milestones. Nurses would inform me of her progress, even if we passed each other in different parts of the hospital. I battled against the onset of tears that sprang to my eyes the day she came off the respiratory monitor and the day she took her bottle from me rather than having nasogastric feeds.

Being Luna's ambassador was easy for me. I felt rewarded knowing that I was helping her and minimizing the impact of the unfair hand she'd been dealt so far. What was challenging about the situation was having to justify my actions. I was regularly questioned about my intentions, not maliciously but from curiosity. Didn't I have somewhere I needed to be? Didn't I need to go and study to pass my exams and be a doctor? The constant surprise I experienced from those around me when I came to cuddle Luna in turn surprised me! Is a doctor so far removed from the role I was carrying out? Was it that unexpected to make time for your patient and do something little, something easy, that was ultimately what they needed most? These reactions triggered me to think about the perception of doctors and the role of 'caring' in the profession.

Doctors are widely appreciated by the community for their knowledge and skill. They save lives and cure ailments. But there were no awesome heroics in my interactions with Luna. I was not resuscitating someone, performing life-saving surgery, or even writing prescriptions to ease pain and fix medical dilemmas. In fact, there was no medical knowledge whatsoever. And while medical knowledge, diagnoses and interventions undoubtedly underpin the profession; the 'care factor' ought not to be overlooked. Perhaps true patient care does not always come with the bells and whistles that we typically preconceive.

Patient-centered care is certainly emphasised in medical training and in hospital policies. It is no secret ingredient to good medical practice. And when I think of inspirational doctor-patient encounters, there is consistently a strong presence of genuine, individualized care for the patient. But there are also many instances I can think of where empathy, emotion and a personal level of care for the patient has fallen by the wayside in clinical practice. There is danger of our patients becoming a catalogue of medical conditions and a list of presenting symptoms. We run the risk of churning patients through a conveyor belt of medical management solutions, without seeing them for who they are. Perhaps I am whimsical, new to the medical world, and have not been accustomed to some of the more harsh realities of time constraints and work pressure; but I like to believe that empathy and medicine are not separate entities. I believe that care can and ought to be integrated into daily practice.

We need to shift our standpoints as doctors from purely clinical mindsets to integrate and give importance to social and emotive patient needs. And for a patient, that may be what they remember the most; not the person who wrote the prescription for the life-saving medication, not the operating staff that all contributed to their successful surgery, but the person that lends enough of their time to get them a blanket because they're shivering. The person who listens, empathises, understands. Having been on the patient side of the fence with a chronically ill and dying close family member, I can testify to the incredible difference that empathy and care brings to the patient's experience. I am privileged to have experienced the patient side of events, because, though tragic and heart breaking, it taught me the phenomenal importance of compassionately driven healthcare and motivates me to act with consideration for the patient's perspective. Luna has taught me similar lessons, but this time from the doctor perspective. I was witness to Luna's needs, and experienced the perspective of a medical person giving help that was not necessarily medically driven, but nonetheless beneficial to the patient. As a doctor, I don't want to lose that heartfelt need I had to hold and help Luna. I graduate at the end of the year, and will soon be thrown into the real medical workforce. I hope to carry with me the same strong desire to help people that inspired this interaction with Luna. Luna taught me that making time to help someone is not wasted productivity – it is the end goal.

I continued to care for Luna and had just celebrated her 60th day of hospital admission when her biological mother walked back on the scene. Luna was reaching medical milestones and was ready to be taken home. Contact was made with the mother and she agreed to come to collect Luna, though she would have to stay overnight to ensure she was safe to look after her. I made sure I was there to meet the mother, and we sat together and talked. I tried to gently impress upon her how important Luna was, and how much she meant to me. While trying not to judge this mother's circumstances, it was an incredibly difficult situation for me, having developed such a connection with Luna, to then be confronted with the woman that had put her in that situation in the first place. The mother left for a cigarette and I held Luna for the last time, rocking her and holding her a little more tightly this time. When the mother returned, I handed Luna over and had to excuse myself to seek refuge in the toilets and cry. I cried because I was no longer able to protect this little baby from what lay ahead of her. I cried

because I felt like the child protection system was letting her down. I cried because I knew Luna more than anybody, and this lady, although she was her mother, was a stranger to her. She would not know that Luna poked her tongue out when she was constipated, that Luna liked the Indigenous lullaby best, and she was not witness to Luna's incredible resilience and medical triumphs in those critical days of her prematurity.

It seemed that Luna had not yet finished teaching me lessons. With time, I was to accept the limitations that come with the role of a doctor. You cannot protect, fix or control things outside the hospital walls. You can only care, then and there, with the patient in front of you. It is perhaps your only chance to show genuine kindness and to hope that your actions might positively influence them. Don't let it go.

This is Luna's story, recalled from true events.

The mother failed her overnight stay with Luna, leaving for a drug hit in the afternoon and not returning. Luna was placed in foster care, though there is a chance that the mother will regain custody in the future.

I think about Luna often and I send a prayer in her direction, hoping that she is well cared for wherever she is. She won't ever know about me, but I won't ever forget her or the lessons she taught me.