



Lucas

Lucas Ethan Wong Kai-En
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Five years ago, Michelle and Patrick lost their second child Lucas to a rare genetic condition. It was a heartbreaking experience, and yet they feel that it has taught them many important things: about staying strong as a couple, about trusting in God and about truly valuing the gift of family.

Written by Patrick Wong, Lucas' father

The discovery

26th October 1999 was supposed to be a happy, exciting day for my five-month-pregnant wife Michelle and I. Already parents to 20-month-old Matthew, we were hoping that the ultrasound that day would reveal a little girl.

But minutes into our session, gender preference became secondary. The scan revealed that the baby boy was smaller than he should have been and that he had a cleft upper lip—telltale signs of a chromosomal disorder, the most common being Down Syndrome.

Our gynaecologist was sympathetic and reassuring. She explained our options—abortion being one of them—and advised us to think them over before seeing her in a week.

Devastated, we stumbled out of the hospital onto Orchard Road, the buzz of human lives cruelly ironic in the light of our discovery. But shell-shocked as we were, we both knew we had to make some tough calls—fast.

The first question: To terminate the pregnancy or not? Our unanimous answer: “No”. The next stumper: What to do now? We had no idea but we agreed immediately that we would face this crisis positively, proactively and as one.

We surfed the Internet and visited the libraries, gathering whatever information we could about coping with a Down Syndrome child. Our aim was to be prepared but keeping ourselves busy this way also forced us not to wallow in misery and self-pity.

But we were soon dealt another blow, more demoralising than the first. The next scan confirmed the baby’s poor growth, leading our gynaecologist to suggest that he had either Patau’s or Edward’s syndrome—both almost certainly fatal.

So just when we had psyched ourselves up for life with a “special needs” son, we now had to readjust to the terrible prospect of our baby’s death.

Coping together

How do expectant parents respond to news like this? How does a couple deal with the sudden plunge from hopeful joy to a whole range of difficult emotions: despair, fear, anger, denial, helplessness?

No doubt about it, a crisis like this can test and strain a marriage, or it can strongly reaffirm its foundations. Michelle and I coped by holding fast to our earlier pact: to face this test together, whatever lay ahead.

And this single-minded commitment to each other—and to the family we were building—served us very well in the months ahead.

But it was not smooth sailing. Such an ordeal can put emotional barriers between spouses. For one, there is the temptation to blame yourself or your partner for the situation, because it is natural to try making sense of your confusion by pinpointing a “culprit”. Or you could give in to hopelessness by retreating into self-pity, abdicating all decision-making to your spouse.

While both reactions may be understandable given the circumstances, you cannot remain a slave to them. The best way to tackle these private traumas is to keep communicating with your partner.

Michelle and I had conflicting views and emotionally-charged debates about choices we had to make but we made the effort to understand where each was coming from. More importantly, we had to always look at the larger picture and agree on important issues.

At the heart of every decision we made was our shared desire to celebrate our baby’s *life*. From what the gynaecologist told us, Michelle’s body should have rejected the foetus, given the probable extent of his genetic disorder. So the fact that he was alive inspired us to be positive.

We decided to give our baby an affirmative name: Lucas Ethan—the first meaning “bringer of light”, for opening our eyes to the silver linings around the clouds; the second

meaning “firm”, for the strength he seemed to infuse us with. His Chinese name echoes the latter: Kai-Ren means “victorious in tenacity”.

Naming Lucas also allowed us to talk to Matthew about him in concrete terms. Not yet two, Matthew was linguistically advanced, and even though he surely did not comprehend everything, he understood that Lucas was his little brother and part of our family. That meant a lot to us.

Helping hands

But no matter what private coping mechanisms are in place, no couple is an island. Never discount the importance of seeking support and solace from others: God (if you are religious), family, and friends.

Michelle and I were blessed with many “ministering angels”. Besides finding solace in prayer, we also had the sage advice of a priest who lifted our drooping spirits: “Don’t despair,” he said. “I believe God gives special children to special parents who have the strength to cope.”

Our parents and siblings took the news bravely and gave us their unconditional backing. They would leave the key decisions to us but made it clear they were ready with help—emotional, logistical, financial—whenever we needed it.

We also found consolation in our friends and colleagues. They offered advice and commiseration, and spoke of our fortitude, which helped us persevere.

And in my cousin and his wife, we had a stirring example of how to cope with bereavement as parents. They had lost their toddler daughter suddenly just two weeks earlier, and together with their families showed amazing acceptance and courage despite their obvious grief.

Ups and downs

If the months leading to Lucas’ birth were testing, the week that followed it was a stressful roller coaster of highs and lows.

He was delivered safely by C-section but was immediately rushed to neonatal ICU even before either of us had a chance to look at him. But the good doctors had their reason: his vital organs were struggling to function.

More than once over the next few days, Lucas’ fragile system collapsed and was revived by the dedicated ICU team. We steeled ourselves for the worst, then despair turned to relief when his condition stabilised and tests revealed that he had neither Patau’s or Edward’s Syndrome.

But any flicker of hope we harboured was soon extinguished completely. Further tests revealed that Lucas had significant genetic material “missing” on chromosome four. The condition was fatal, after all.

farewell, my child

We drew close and prayed. We registered his birth and had him baptised. We visited him twice a day. Unable to cuddle him because of all the life-sustaining tubes attached, we stroked him, read and sang quietly to him and told him what a fighter he was.

After a week, my wife and I decided not to delay the inevitable. We set a date and time for Lucas to be taken off life support—it was the hardest choice either of us ever had to make, involving lots of discussion, soul-searching and tears.

It was another priest—the one who baptised Lucas—who again put things in perspective for us: “Your decision to let Lucas go is not a betrayal. You have already done the right thing by giving him your love and the chance to be born.”

So the next day, as the doctors gradually lowered the life support, and with our families around us, we finally got to hold Lucas in our arms as his little life ebbed away.

The year after

Lucas’ wake, funeral and cremation were emotionally draining but at least we were surrounded by family and friends.

The full pain of our loss—that aching emptiness—only hit us later. Our home seemed strangely barer, even though Lucas had not actually lived in it. The real gap was an emotional one and the grief took a good year to subside.

At the start of that period, we were asked by the doctors who took care of Lucas to help initiate a support group for bereaved parents. They felt that we had coped admirably with the situation and that we could share meaningfully with couples going through a similar ordeal.

We considered it for a few days but eventually declined. While we felt that this may have been a call from God, via Lucas, to minister to others, we were still feeling the pain of the experience too keenly.

Refocusing on Matthew—who, unfortunately, had to take an emotional back seat during those difficult months—helped us to heal. We started appreciating him with a new depth, cherishing every moment with him much more.

Needing time and distance away from it all, we took a family holiday in Australia some months later. We had a great time, and started feeling that it was all right to be happy again.

Becoming parents again (and again!)

But even though our lives gradually returned to normalcy, there was still that gaping hole that Lucas’ passing had left.

This was felt especially acutely by Michelle. Make no mistake—my wife is an incredibly strong person (stronger than me in so many ways), but the loss hit her very

hard. She desperately wanted to conceive again, not so much to “replace” Lucas, but to resume building our family.

It took us just over a year before we were successful again. It was a stressful period of trying and failing (odd, because conceiving the two boys had been a cinch), but we finally got good news in February 2001. And the news got better some months later: “You’re going to have a princess!” our gynaecologist announced.

To say that I was ecstatic would be a huge understatement. I had always wanted a little girl and according to Michelle, I wore a huge grin for weeks after the news. But more than joy, there was also a great sense of thankfulness in us, especially after each scan that showed how well our girl was doing.

Sara arrived in November 2001 and our family felt complete. Matthew continued to amaze us with his powers of speech and reading, while Sara thrilled us with her easy ways—she ate voraciously and slept through the night at eight months old.

Still, God had one more surprise for us: the unplanned conception of our third son Zachary. Born in June 2003, he has added another dimension to our lives by proving to be a “quick mover”, with his hyperactive dashing around the house and eagerness to scale anything that looks climbable.

It is sometimes tempting to see Zachary as a divine gift, a heavenly “substitute” for Lucas. But if there is one thing we have learnt, it is that each child brings different challenges but each child can also bring different blessings—if we are able to see these challenges as blessings.

And that neatly sums up Lucas, the little boy who lived for just eight days but whose brief life brought so much new meaning—and closeness—to ours.

God's Lent Child (excerpt)

We will shelter him with tenderness
We'll love him while we may
And for the happiness we've known
Forever grateful stay.

– Anon.