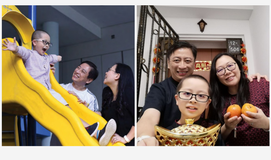
Why can't I take Papa's place?: Late S'porean boy who had cancer 4 times cried after father got colon cancer

Shirlie of Sir Raphael Lee scored 220 for his PSLE but passed away before he could collect his results. More than just a bright student cut down in his prime, he was a tenacious fighter and loving son.

Joshua Lee | November 29, 2020, 05:06 PM



By now you might have heard of Raphael Lee.

The 12-year-old student from Alexandra Primary School passed away earlier this month, before he could collect his PSLE results.

His death marked the end of a painful struggle with cancer that lasted nearly his entire life.

The late Raphael Lee passed away in November this year, just before he could collect his PSLE results. Image courtesy of the Lee family.

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Diagnosed with rhabdomyosarcoma (a rare type of cancer that forms in muscle tissue) when he was only 8 months old, Raphael would go on to have osteosarcoma (a type of bone cancer) in his left forearm at the age of eight.

Despite efforts to treat his bone cancer, it came back again and again.

At the age of nine, a tumour was found in his left wrist. He had his left arm amputated in a bid to stop the cancer from spreading.

When he was 11, the cancer was found again, this time in his right collarbone and one right rib. Those were removed as well.

This year, when he was 12, Raphael and his family received another blow: nodules were found in his lungs, indicating the possibility that his bone cancer had progressed to a secondary cancer.

The boy underwent surgery in April and May to remove the nodules. In August, however, they came back with a vengeance.

Raphael went into the operating theatre again on November 10. Three days later, he passed away from complications that arose from the surgery.

Maturity of thought and selflessness rarely seen in 12-year-olds

"We knew that he would not have a complete lifespan but we just didn't know that that day — November 13 — was going to be his last day," says Winnie Lee, Raphael's mother.

It's been two weeks since Raphael's passing and I'm meeting his parents — William and Winnie — as well as his parish priest at the Church of Saint Bernadette.

Towards the end of his life, the family came here often to pray. In fact, the family was here the day before Raphael's final surgery, kneeling at a grotto with a statue of the Virgin Mary, interceding fervently for a miracle.

To be honest, Winnie and William thought that the final surgery would give them another year with their son; collecting his PSLE results on his behalf was never part of the plan.

Raphael's tenacity earned him the ALPS (Alexandra Primary School) Warrior Awards. Image by Joshua Lee.

Raphael's PSLE score — 220 (two "A"s and two "B"s) — would have clinched him a spot in the Express stream. It is even more admirable considering that Raphael only completed one semester of school each year since he was Primary 2.

There's no doubt that Raphael was a bright boy, and his achievement, tenacity, and hard work are to be lauded — as many other media outlets and readers have done.

Yet, listening to the stories about Raphael, what moved me most was how he showed maturity and selflessness rarely seen in 12-year-olds.

Grieving over his lost arm in private, but strong in public

Raphael adapted pretty well to the loss of his left arm — in public.

People who visited him in the hospital after his amputation were surprised to find him so cheerful, says William. But it was a brave front, possibly so as not to let others worry, he adds.

> "Months after the amputation, there were times that he hid away and cried to mourn the loss of his arm."

He would hide himself in the toilet at home for long periods of time, adds Winnie.

> "The moment I knock on the door to check on him, he would open the door and tell me: Mummy I'm OK. I was just grieving over my arm."

Crying was simply Raphael's way of regulating his emotions, says Winnie. He didn't dwell unnecessarily on the fact that he had one arm. Neither was he bitter about it.

Raphael and his family. Image via Brightpatch.

It wasn't as easy for William, who lets on that for years, he struggled with himself for "failing as a father" to save his son's arm.

> "Of course, all my friends — all those who were fathers — said you have already done more than what a father would do. This was beyond your control."

But the guilt still ate at him for three years. William mustered up the courage this year, just before Raphael's final operation, to apologise for not being able to help his son keep his arm.

The boy broke into tears and hugged his father tightly, whispering in his ear: "I didn't blame you."

"So this is something that is really dear to me now," William says quietly.

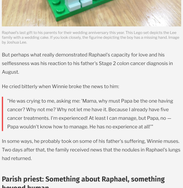
Why not let me have Papa's cancer?

William and Winnie understood that beneath his cheery exterior, Raphael chose to take on the burden of his cancers on his own, hoping that his parents would not worry unnecessarily.

And so, while he would pour out his fears and grief to his social workers from the Children's Cancer Foundation, the boy hardly ever unloaded his burdens onto his parents, whom he loved deeply.

Every year, he, with the help of his grandmother, would plan an elaborate dinner to commemorate William and Winnie's wedding anniversary. Grandma would do the cooking while Raphael assisted in the kitchen and doubled up as a waiter.

This year, there was no dinner, but William chuckles as he brings out the gift that Raphael made for them:



Raphael's last gift to his parents for their wedding anniversary this year. This Lego set depicts the Lee family celebrating under Pi (a book character). If you look closely, the figurine depicting the boy has a missing hand. Image by Joshua Lee.

But perhaps what really demonstrated Raphael's capacity for love and his selflessness was his reaction to his father's Stage 2 colon cancer diagnosis in August.

He cried bitterly when Winnie broke the news to him:

> "He was crying to me, asking me: 'Mama, why must Papa be the one having cancer? Why not me? Why not let me have it. Because I already have five cancer treatments. I'm experienced! At least I can manage, but Papa, no — Papa wouldn't know how to manage. He has no experience at all!'"

In some ways, he probably took on some of his father's suffering, Winnie muses. Two days after that, the family received news that the nodules in Raphael's lungs had returned.

Parish priest: Something about Raphael, something beyond human

Raphael was named after an archangel, and in many ways, he was an angel to the people around him, including Reverend Father Kamelus Kamus, the boy's parish priest at the Church of Saint Bernadette.

It's been two weeks since Raphael's passing, but it is evident that the priest, who stops several times during our chat to collect himself, is still deeply affected by the passing of one of his flock.

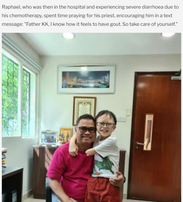
Father Kamelus (or Father KK as he is more commonly known) last saw the boy on November 9, one day before his operation. The Lee family had come to the Church of Saint Bernadette to pray and receive the Holy Communion.

He lets on that Raphael was deeply afraid, as any normal 12-year-old would be. Yet he showed resilience, courage, and most of all, a capacity to care for others who were suffering.

> "There is something in the boy that you cannot really...there is something beyond human."

The parish priest shares that he had gout in August.

Raphael, who was then in the hospital and experiencing severe diarrhoea due to his chemotherapy, spent time praying for his priest, encouraging him in a text message: "Father KK, I know how it feels to have gout. So take care of yourself."

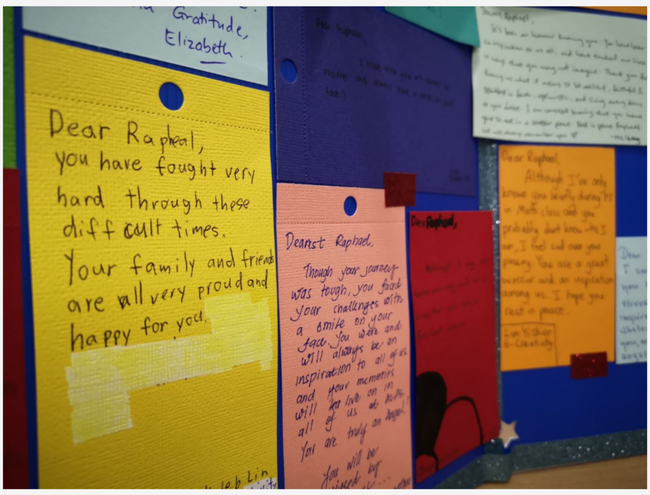


Raphael and his parish priest, Father Kamelus Kamus. Courtesy of Father Kamelus.

"What really touched me was that the following morning, he said: Father KK, did you take your gout medicine already?" chuckles Father Kamelus fondly.

To many, what Raphael went through within the short 12 years of his life was senseless. But to Father Kamelus, the boy's life demonstrated faith in action.

> "Faith, translated into surrendering, made him brave enough and strong enough...we may have faith, but we need to learn to live this kind of faith, even in the dark moments of our lives. And that's what I learned from him."



It wasn't just Father Kamelus who was touched by Raphael. Students and teachers from Alexandra Primary School penned farewell messages for him, detailing how he touched their lives. Image by Joshua Lee.

Winnie: I'll be proud of him forever

The day before our chat, William and Winnie went to Alexandra Primary School to collect Raphael's PSLE results.

What would you say to him if he was here, I ask.

Winnie's answer is quite telling: "Though my boy has no distinctions, it's okay. I mean, I'm very proud of him."

> "In fact, to me, I find that he has already passed his test of life with flying colours.
>
> I'll be proud of him forever."

Raphael and his family. Courtesy of the Lee family.

Stories of Us *is a series about ordinary people in Singapore and the unique ways they're living their lives. Be it breaking away from conventions, pursuing an atypical passion, or the struggles they are facing, these stories remind us both of our individual uniqueness and our collective humanity.*

Top images via SingHealth, Lee family.

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