

# “There’s still so much I’m lucky for”

By HCA Hospice Care Community Relations Team • Photos by Bob Lee  
HCA Hospice Care

“I’ve always loved doing business. When I was little, I sold photographs of celebrities. Now, I sell things on the internet.”

“I feel satisfied when people are happy with my products. What’s more important – that they buy things from me not to help me, but because they really like the product.”

Thirty-four-year old Vivian Goh has been bed-ridden since her twenties. She suffers from Spinal Muscular Atrophy Type 2, which has caused her muscles to deteriorate gradually over the years.

It started with her legs.

It’s crept upwards ever since. Now, she isn’t able to swallow, and can only move two fingers on her left hand.

That doesn’t stop her, though.

Stacking two pillows just so on top of Vivian’s belly, her mother Ivy wheels over a Hello Kitty laptop, mounted on what looks like a robotic arm. She arranges first the mousepad, then the mouse, then Vivian’s hand, carefully on the stack of pillows.

Slowly, using just two fingers on her left hand, Vivian calls up a screen keyboard on her laptop and begins to type us an email, even as she checks on her online game character and logs in to Facebook, stopping briefly to show us her online retail store (<https://www.flickr.com/photos/vgshoppingmall>).

Through Facebook, her online game, and her business, she gets in touch with people from Taiwan and China. “They don’t have a clue that I’m like this,” she says.

She’s never been to school, but has taught herself through assessment books and textbooks, and learned English from television.

“I’ve been like this my whole life, so you could say that I have gotten used to it. I think it might be harder to cope with if I had grown up with a normal body,” Vivian confides.

Her mother Ivy has been by her side since birth – and it’s not been easy, to say the least. She brought up both Vivian and her brother on her own since Vivian was three years old, working to support the family even while catering to Vivian’s needs.

Now, it’s not an exaggeration when we say she spends all her time by Vivian’s side, singlehandedly managing her oxygen, feeding, cleaning, and medications. She’s even picked up basic physiotherapy.

“My biggest regret is not spending more time and attention on my older son. People also ask me what I’d do if I had more time. I would definitely offer support to other parents like me.”

## About HCA Hospice Care

Established in 1989, HCA Hospice Care is Singapore’s largest home hospice provider. It also offers a day hospice programme for mobile patients who do not require round-the-clock nursing care. Its multidisciplinary teams of doctors, nurses, medical social workers and counsellors make 37,000 home visits each year to support patients with life-limiting illnesses and their families. Besides its headquarters at Jalan Tan Tock Seng, it has four satellite centres island-wide.

It’s not difficult to see where Vivian gets her sunny disposition and good humour from. Ivy’s irrepressible cheeriness lights up the room, and we’re not the first to notice this.

“A lot of people ask, how come we’re so happy,” shares Ivy. “I believe that we should be positive. To be happy, is a good thing. If we live happily, good health will follow.”

Yet both Vivian and Ivy are realistic about the disease, and the way it is bound to deteriorate as the years go by. Vivian’s had to be rushed to the ICU several times, with doctors preparing Ivy for the worst. Thankfully, the natural fighter Vivian pulled through each time.

“I struggled a lot with myself when doctors told me that it wasn’t looking good. Should I ask them to give up, or continue fighting on?” Ivy shares.

Vivian added, “I’ve discussed with doctors, and have informed them not to prolong my life if I don’t show any brain activity anymore.”

“Every day, Mum makes me laugh by telling me jokes, acting in a very ‘cartoon’ way, and using silly voices to make me happy,” says Vivian. “I want to thank her for making me happy throughout my entire life. Without her by my side, my life would be completely different.” ❤️

