



# Life Is Beautiful

By Dr Chan Yeow

**“PRAISE THE** Lord, praise the Lord, let the earth hear His voice...” The refrains of the hymn “To God Be the Glory” filled the HDB void deck. The atmosphere was festive. The family members were smiling. *This did not seem like a wake at all...*

Mdm Hoo Lai Lai (Li Li in Mandarin, meaning “beautiful”) originally developed signs of spinocerebellar ataxia during pregnancy at the age of 31, presenting with ataxia, nystagmus, and ophthalmoplegia. I first got to know her in February 2013, after receiving a request from my Neurology colleagues at Tan Tock Seng Hospital (TTSH) to perform a percutaneous tracheostomy for her. She had been admitted to the neurointensive care unit for recurrent pneumonia with hypercapnic respiratory failure, and had become ventilator dependent. I felt hesitant when I heard about her diagnosis of spinocerebellar ataxia, wondering if a tracheostomy might be a life-extending procedure that would simply impose more burdens on her and her family.

“Do you know that with the tracheostomy, she would be quite unlikely to speak audibly again? She might live on for a few months or a year or two, and still eventually die... Is this something she would really want?” I pressed on, rather insensitively. Albert,

her spouse, was hunched and taciturn. It seemed as if the whole weight of her illness and their family were upon his shoulders. They had a son who was still in his teens. Would they be able to cope? I did not want her to die of neglect, with huge bedsores.

“Doc, I am her husband. I have looked after her for the last 17 years. All of you tell me she has no hope. She has expressed that she is not ready to leave us yet, and she wants to live. I will look after her.” He stated this in a calm but weary tone, but it was one that did not inspire much confidence. We shook hands, and thus our fascinating partnership began.

True to Albert’s declaration, the discharge home was fairly fuss free. Our nurses called them and visited whenever necessary to conduct blood investigations, perform nasogastric tube changes, or attend to other nursing issues. I came by every two months for the tracheostomy changing, and did a general systems review on each occasion. Replacing a cuffed tracheostomy tube can be a fairly traumatic experience for the patient, the doctor and any observer. This is because the stoma often narrows and granulation tissues form with time, resulting in difficulties for both removal of the old tube and insertion of a new one, accompanied not infrequently with some bleeding.

Lai Lai always greeted me with a broad smile whenever I arrived at her house. My team and I would often find her listening to hymns and songs of praise with her iPad, and she would be attempting silently to sing along. We had been unsuccessful in initiating ventilator-assisted speech via a deflated cuff for her (some other patients with tetraplegia and Duchenne muscular dystrophy can speak excellently despite being tracheostomised and 24-hour ventilator dependent), because she needed the high positive pressure and would develop atelectasis and pneumonia each time we tried cuff deflation. However, she adapted by learning to use a word chart with Chinese characters, as well as an iPad. With these, she was able to communicate not just material and physical needs, but also abstract thoughts and emotions. At the end of each tracheostomy changing, she would express her gratitude, holding our hands, and praying silently in her heart for us and all our other patients.

As Albert had promised, they coped well, and soon we began to hear wonderful accounts of her returning to normal activities. Her family members and domestic helper would regularly bring her in a wheelchair to the nearby park or to the supermarket (she was 24-hour ventilator dependent but modern home ventilators are compact and

portable). She began going to church regularly, and was an inspiration to her friends. In January this year, during the TTSH Occupational Therapists' Week, Prof Philip Choo, our Chief Executive Officer, met her and thanked her for being such an inspiration to our other patients.

This was not without problems, though. I did not get to meet Albert during my home visits. His mother-in-law would tell me how she was worried for his health, as he had to work longer hours to support the family, and still nurse his wife in the evenings in order to give the helper some respite. She reported that he often had backaches and neckaches, which he would quietly shrug off.

### 600 days of joy and beauty

It was a very different Albert I met at the wake. His eyes now gleamed with a combination of wistful longing for his wife; joyous hope that she was now in a better place, and that he too would one day go there; and a quiet satisfaction that he had "fought the good fight". He showed us photograph after photograph of them both, especially in their younger days. More surprises, but it all fit...

There Lai Lai was, with a corset and Nordic walking poles, on Bukit Timah Hill. This was before the ataxia and neuromuscular weakness had completely robbed her of mobility. There she was again, but in a wheelchair, surrounded by teenagers and young children somewhere in

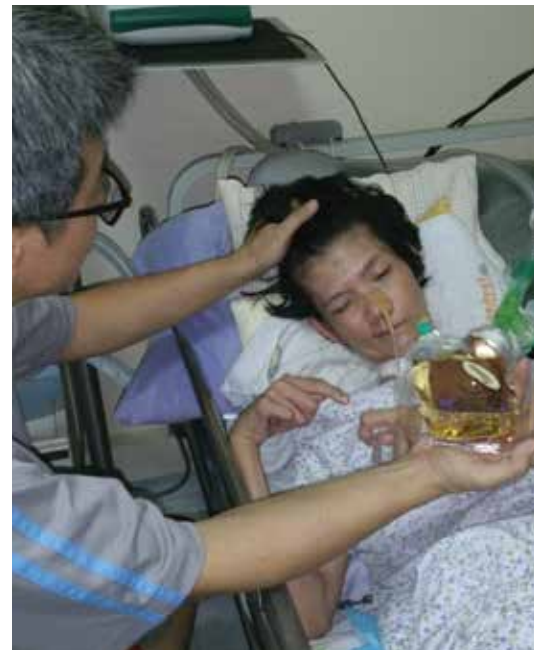
rural India. She was on a mission trip, visiting an eye surgery facility in India, even though she herself needed a wheelchair. We saw that she was never without her trademark radiant smile in all these pictures. And knowing her, I believe she was more concerned for the folks around her than for her own discomforts and inconveniences.

Life brings challenges, illnesses, injuries and death. It is tempting for us healthcare workers to want to control everything, but each patient and family have their own pace and rhythm. From Lai Lai and Albert, I learnt that suffering could be transfigured into something joyous and beautiful. Her additional 20 months on a ventilator, in a wheelchair, could have been merely 600 days of suffering. But she, with him, managed to turn them into 600 days filled with "I love you's"; smiles and prayers, touching so many lives in the process.

"Yes, Doc. Life is beautiful. What an appropriate title. Please write it...!" With these parting words from Albert, I gained the courage to share Lai Lai's amazing story. ■



*Dr Chan Yeow is an anesthesiologist and intensivist at TTSH, and Director of the Home Ventilation and Respiratory Support Service. He gets a great kick when ventilated, tracheostomised patients can speak audibly, return home and do things they enjoy. His other interests are in philosophy, medieval history, Romance languages and calisthenics.*



**Facing** Lai Lai enjoying a Saturday afternoon at Albert's 94-year-old client's house

**Top** Lai Lai and Albert (centre) with Prof Philip Choo at TTSH Occupational Therapists' Week 2014

**Bottom** Albert and Lai Lai celebrating her 49th birthday on 21 August this year – with a simple cake, just for looking and smelling

## Home mechanical ventilation

Patients with respiratory failure may suffer impairments with gas exchange caused by alveolar or distal airway issues. These patients may benefit from oxygen therapy, bronchodilators, diuretics or antibiotics, depending on the reason for gas exchange impairment.

Conversely, patients with reduced ventilatory capacity are unable to adequately shift gas in and out of the lungs, due to problems with the brain (eg, central hypoventilation), nerves (eg, amyotrophic lateral sclerosis and spinal cord injury), muscles (eg, muscular dystrophies), or increased load (eg, kyphoscoliosis and morbid obesity). Such patients require mechanical ventilation to maintain their physiology.

Home ventilation aims to sustain patients' functions and quality of life, while improving survival. The patients should be stable, cognitively intact, and keen on this treatment. They and their families must understand the risks involved and be willing to undertake the responsibility of care.

The TTSH Home Ventilation and Respiratory Support Service is a multidisciplinary team that provides coordination, training and follow-up for complex home ventilation patients, like those on tracheostomy ventilation, near continuous non-invasive ventilation, and those with disabling, progressive neurological diagnoses.