



Mr Kelvin Chan and Ms Tay Shuhui with the clothes that belonged to their daughter Kaelyn, who died three years ago after her life support was withdrawn. Kaelyn was diagnosed with spinal muscular atrophy (Type 1), and had a severe chest infection in April 2015 that led to an interruption in blood flow to vital organs such as her brain. She was three years old when she died. ST PHOTO: KEVIN LIM



As Kaelyn's muscles wasted away, she could move only her arms. PHOTO: TAY SHUHI

QUALITY OF LIFE MORE IMPORTANT

Even if we did the tracheostomy, she would still be sick and so her life would still be in danger. So we drew the line there and decided that we didn't want to put her through the pain and that it was more important for her to have quality of life.



**MR KELVIN CHAN**, on rejecting a procedure that would have helped his daughter Kaelyn breathe.

NO REGRETS

If we were to go back in time, we would probably make the same decision again.



**MR CHAN**, on the decision to withdraw life support from Kaelyn.

# No regrets in letting go of daughter

For more than a year as they watched their daughter grow up, Mr Kelvin Chan and Ms Tay Shuhui avoided one topic.

Since their daughter Kaelyn's first hospital stay when she was 10 months old, doctors were already asking them to think about what they wanted to do if her condition deteriorated further and if her ventilation mask was unable to keep her breathing.

They could either do a tracheostomy – opening an air passage in her neck to help her breathe – or pull the plug to let her go.

Kaelyn, their only child, was diagnosed with spinal muscular atrophy (Type 1) when she was four months old. The expected lifespan for people with that type of neuromuscular disease is usually less than two years.

With the clock ticking, Mr Chan, a business development manager, and Ms Tay, a secretary, tried to keep Kaelyn as happy and comfortable as she could be.

As her muscles wasted away, Kaelyn could move only her arms. So



Alfie Evans died in April nearly a week after his life support was withdrawn. PHOTO: AGENCE FRANCE-PRESSE



Supporters of the fight to save baby Charlie Gard at a rally outside the High Court in London last July. PHOTO: EPA-EFE

## Singapore yet to see UK-style test case

Singapore has yet to have a test case of desperate parents fighting doctors in court to prolong treatment for their children, even when it may seem inhumane.

But there were two recent cases in Britain that captured the world's attention – 23-month-old Alfie Evans

died in April and 11-month-old Charlie Gard died last year after the courts declared that life support should be withdrawn, both against the parents' wishes.

Britain's 1989 Children's Act says that when a child is at risk of harm, the state can and should intervene.

In Singapore, the care plan for each patient is based on the best interests of the patient and in consultation with the patient's family, said the Ministry of Health.

Dr Chong Poh Heng, medical director at HCA Hospice Care, said that if doctors disagree with the parents' decision, they can discuss the case with the ethics committee in their hospitals, then return to engage with the parents.

In some cases, parents can also potentially seek treatment from another medical team that is prepared to take over the case, Dr Chong added.

Ultimately, if the parents are still unable to reach an agreement with medical professionals, the case may then be taken to court, he said.

**Janice Tai**

her parents got her toys of different textures and sounds to engage her.

She also enjoyed making noises by hitting a stick on a drum.

Though she was attached to five different machines – ventilator, suction pump, machine to track her pulse and oxygen level, oxygen tank and milk pump – the little girl loved going downstairs to watch other

children play at the playground.

Said Ms Tay, 36: "You would see her smiling when she was downstairs and she fussed when it was time to go home."

Kaelyn was unable to speak but her parents understood her as saying "yes" when she gave a short grunt and "no" when she gave a longer grunt.

By late 2014, Kaelyn was getting weaker and had to be hospitalised more frequently due to infections.

By then, after prompting by doctors to think about Kaelyn's future, the couple decided that they did not want Kaelyn to go through a tracheostomy.

"Even if we did the tracheostomy, she would still be sick and so her life

would still be in danger. So we drew the line there and decided that we didn't want to put her through the pain and that it was more important for her to have quality of life," said Mr Chan, 37.

In April 2015, Kaelyn had a severe chest infection that led to an interruption in blood flow to vital organs such as her brain.

Her brain lost significant function due to the lack of oxygen.

Said Mr Chan: "It was as if our daughter had made up her own mind to go and made it easier for us to decide because it was not an easy decision."

Kaelyn's parents decided to withdraw life support and took her home to die.

On the evening of April 23, 2015, Dr Chong Poh Heng, medical director of HCA Hospice Care, pulled the plug that turned off Kaelyn's ventilator in her room.

She was three years old. Her distraught parents wiped down her little body with a wet cloth and put her in a yellow dress and pink cardigan. It was the dress she wore for Chinese New Year that year. They spent the night with her.

Kaelyn was cremated the next day and her ashes scattered at sea the day after.

Since then, Mr Chan and Ms Tay have been sharing their experiences with other parents of children with spinal muscular atrophy.

"We just share our experiences with them but they have to make and live with their own decisions," said Mr Chan.

Three years on, the couple have no regrets about the major decision that they made.

They are not trying for another child as they said there is a 25 per cent chance of the child having spinal muscular atrophy.

"If we were to go back in time, we would probably make the same decision again."

**Janice Tai**