

# Life support: To switch off or not?

## Issue in spotlight after recent cases involving British children

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Her parents did not want to give up on her, even though the 16-year-old had an incurable neurodegenerative condition and had been hooked up to life-support machines at home for more than five years.

So when she had a bout of chest infections two years ago that led to her organs failing, they persisted in treating her, and she stayed for almost a month in the intensive care unit of a hospital in Singapore.

Said Dr Chong Poh Heng, medical director at HCA Hospice Care, who treated the girl: "It was certain to us that the child was going to die despite all that we did, and her quality of life was doubtful, given the aggressive treatment and being kept alive on machines."

As treatment continued according to the parents' wishes, doctors, nurses and social workers started

feeling uncomfortable about it. They asked themselves: Are we prolonging her suffering? Is this standard treatment? Should we stop treatment?

The question of when and whether life support should be withdrawn for the terminally ill was recently discussed globally over the case of 23-month-old British toddler Alfie Evans, who died days after his life support was withdrawn in late April.

Alfie's story captured the world's attention when his parents fought a lengthy legal battle against hospital administrators to not have his life support turned off and for the right to have him treated overseas.

A similar high-profile case involving another British infant, 11-month-old Charlie Gard, took place last year.

Dr Chong said: "The case of the 16-year-old girl here could have turned into an Alfie Evans or Charlie Gard case if the medical team was harder in its approach."

He added: "But it was not about the fear of litigation. The healthcare team recognised that the parents found it hard to let go and she was

treated till she died shortly after."

Dr Chong said that despite some concerns from the medical staff, the girl was not suffering intolerably, otherwise they would not hesitate to stop treatment.

The family is not being named due to patient confidentiality clauses.

Cases where parents push for aggressive medical treatment for their children and find it hard to let go are not rare. Dr Chong, who started the only community paediatric palliative care service in Singapore in 2012, called Star Pals (Paediatric Advanced Life Support), at HCA, said he sees four such cases a year.

Star Pals has about 10 children on life support now, out of the 60 currently in its care.

At the heart of the issue is what constitutes "the best interests of the child" and who gets to determine that, especially if it is difficult to draw out the voice of the child.

Dr Chong said children tend to be medically treated more aggressively than adults.

"Health professionals and parents may have more difficulty accepting the condition and letting go because so much future is at stake

and they try very hard," he said.

In the case of the 16-year-old girl, her parents adored her and their lives had revolved around her for the last decade. They prayed and waited for a miracle.

So when they sensed that the medical team seemed to be giving up on their daughter, they wrestled with trusting them, said Dr Chong.

They were harsh with the staff and asked them so many difficult questions that some of them were afraid to enter the hospital room.

In response to queries, the Ministry of Health (MOH) said there is no difference in the standard of care for life support rendered to children and adult patients.

When curative measures are no longer possible, the goal will be to provide comfort and care to patients and their families, it added.

In such scenarios, MOH said the medical team would work closely with families to take into account their needs, views and wishes.

Doctors are also guided by the Singapore Medical Council Ethical Code and Ethical Guidelines to ensure there are benefits and that no harm is done, said MOH.

Life support is typically delivered as part of inpatient care, so government subsidies and financing schemes for inpatient hospital care would apply.

Not every child is hanging on to life support just because his parents are unable to let him go, said Dr Chong. Many children can live for years on life support, with a decent quality of life.

Ms Vivian Goh, for instance, was not expected to live past the age of 12 when she was diagnosed with a neuromuscular condition as a toddler. Today, she is 38 years old.

Since she was young, she has been hooked up to a medical ventilator overnight and to an oxygen tank permanently.

For business development manager Kelvin Chan, 37, and secretary Tay Shuhui, 36, the fact that their daughter sustained brain damage made the choice to pull the plug "easier" (see other report).

Said Mr Chan: "There is no right or wrong decision. Ultimately, the parents are the ones who have to live with the decision they have made."

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