

Being able to stay home a blessing

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Every day little Syifaa Taufan wakes up in her own bed is a good day.

Never mind that she is hooked up to a ventilator and oxygen concentrator to help her breathe, and has three other machines to feed her milk, remove phlegm and monitor her blood oxygen levels.

Less than a year ago, the two-year-old, who suffers from a congenital neuromuscular disease, was barely home for a month at a time.

Her father, Mr Taufan Rayis Mochamad, 35, estimates that his little girl has spent nine months of her short life in hospital, mainly in the intensive care unit. But the last seven months have been free of all that, a "good step forward", Mr Taufan tells The Sunday Times.

Syifaa's breathing is weak and she finds it difficult to swallow. Phlegm can end up in her lungs, putting her at risk of chest infections. It was her recurring bouts of pneumonia that kept landing her in intensive care.

Her parents eventually decided to have a tracheotomy performed, where a tube was placed into her windpipe through an incision in her neck. This made it easier for her to breathe and for her parents to re-

move phlegm from her airways. She has not been hospitalised since she was discharged last December.

But getting to that point was an arduous journey filled with arguments with doctors and nurses, and denial, Mr Taufan admitted.

"At first, I did not believe (that my daughter was sick)... there were no problems when she was in my wife's womb," said Mr Taufan, who works in a shipping firm.

He described his early meetings with the medical team as "wars" where he would go against their advice, even taking Syifaa home when she was still unstable.

"I was hard-headed," admits the father of three other daughters. "My other daughters were well, why should she be unwell?"

Twice, the family backed out of the tracheotomy, and twice, Syifaa was in critical condition.

Last September, when Syifaa's lungs collapsed, they finally agreed to the procedure. "We nearly lost her," Mr Taufan said.

And that was the turning point.

While initially worried about maintaining the tracheotomy, Madam Sofa Muhamad, 31, Syifaa's

mother and main caregiver, now confidently suctions mucus from the tracheostomy tube every three to four hours, and cleans and changes the tube's dressing.

The housewife also feeds Syifaa milk through a gastric tube and helps to stretch her arms and legs.

Syifaa is visited every one to two months by Dr Thong Wen Yi, 37, who heads the National University Hospital (NUH) Paediatric Home Care Programme, and Ms Elaine Hor, 39, an advanced practice nurse.

They check her vital signs and how well she is breathing, and test her phlegm for viruses or bacteria, among other things. They have been supporting the family for two years.

Because of the home-care help, Syifaa has outpatient appointments at the hospital only once every two months, compared with two to three times a month in the past.

The experience also made Mr Taufan determined to do his bit for very sick children.

Six months ago, he started volunteering at Star Pals (Paediatric Advance Life Support), where he ferries children with complex medical needs to their medical appoint-

ments once or twice a month.

"After all, the patient's parents are in the same boat as me. How they feel is how I feel," he said, adding that he is also grateful to a Star Pals nurse who makes regular visits to Syifaa. The family has received much help from NUH and Star Pals, through subsidies and even some free medical equipment.

For Syifaa's family, the little girl has never been considered any-

thing but a blessing. Though they still hope for a miracle cure, Syifaa's family has accepted her condition.

That includes her three big sisters, Sameera, 10, Haifa, nine, and Hilwa, five, who say Syifaa is the "most special" sister. They spend time caressing her, playing with her and talking to her.

"They will notice when she is unwell or if something is wrong with her," said Madam Sofa. Mr Taufan

added: "I asked (my two elder daughters) what they want to be in future and they said they want to be doctors. They want to cure Syifaa."

Samantha Boh



VIDEO

Home-based care helps two-year-old Syifaa.
<http://str.sg/4EW4>



Dr Thong Wen Yi checking Syifaa Taufan's condition, with the assistance of advanced practice nurse Elaine Hor, as Syifaa's mother Sofa Muhamad looks on.

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