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Loving, playing, learning: A childhood for cancer kids

Dian Kuswandini, The Jakarta Post, 13 Feb. 09, Jakarta

"Hi little brother, will your eyeball also be removed like mine?"

Four-year-old Aisya Putri hugged one-year-old Fesa Rahmandika, planting a warm kiss on the little boy's cheek.

These two children are not siblings; they are strangers. But Fesa's half-closed eyes quickly attracted Aisya's attention and affection.

"He can't see [clearly], just like me," said Aisya, an eye cancer survivor. "And he has no hair, too, like me," she grinned, touching the fluffy strands of hair on her head - all that's left after chemotherapy.

It is unexpected to find such good humor in a little girl like Aisya, who has just lost one of her eyes. Six months ago, her life took a sudden turn and she was forced to battle bravely against cancer. She was diagnosed with retinoblastoma and underwent surgery to remove her right eyeball.

Nine-year-old Yulia Pratami was diagnosed with ovarian cancer; she lost her uterus.

"The doctor told me that I no longer have a uterus. He can say that, but it's all up to God to decide the rest," Yulia said, with the wisdom one might expect of an adult.

After less than three years of treatment, Yulia has blossomed into a brave little girl with, some would say, even more confidence and charisma than before.

"I know a girl older than me who died because of ovarian cancer, but I have to keep my spirits up and be strong," she said.

Yulia and Aisya are just two of the many children suffering from cancer, children who are courageous enough to tell people about their illness. Months of medical treatment have isolated them from their friends and the outside world, but one place in Jakarta has restored their confidence.

That place, called Rumah Kita (Our House), has reunited the child cancer survivors, allowing them to experience sickness with some happiness. `This is not just a house built with bricks.

It's a home built with love," said Ira Soelistyo, Rumah Kita's founder.

Not only does Rumah Kita give a shelter to children from low-income families, it also provides them with education and, most importantly, affection.

"Many people say to me, 'Those kids may not live much longer. Why do you bother spoiling them with a cozy place to live and education?'" said Ira, who also co-founded the Indonesian Care for Cancer Kids Foundation (YKAKI).

"And I said: Even if they're going to die, these kids still have the right to get the best of everything, because basic rights apply to both healthy and sick children."

Unfortunately, Ira added, not many people understand this matter of rights for children with cancer. She recalled the first time she brought children to live in Rumah Kita - neighbors started to complain about the kids and reported them to the neighborhood unit head.

"They were afraid they would get infected by the diseases," Ira said of her bitter experience. "We had to invite some experts on cancer to convince them that cancer is not contagious."

Even now when some people still label children negatively, Ira said parents must not lose confidence.

"Treatment for children with cancer is different to that for adults because children greatly depend on the parents for their remedies," Ira said.

And importantly, she said, children with cancer should still be allowed to be children.

"Don't keep your children isolated. A child's world is all about play," said Ira.

"Take them out to play; make them happy. This way, not even cancer can traumatize them."

Ira's own son died from leukemia in 2006. Her experiences in taking care of her son for more than 20 years inspired her to share her positive attitude with other parents of cancer survivors. After her son died, Ira and two friends Pinta Manullang and Aniza M. Santosa established YKAKI.

With its main goal to improve the quality of life of children with cancer, the foundation set up Rumah Kita and Sekolah-ku (My School) in Jakarta. "Many of the children with cancer that I knew had to discontinue their education because of the medical treatment. This is just not right. Education should not be taken away from sick children," Ira said.

By providing the children with the chance to enjoy what had been taken away from them -

education and quality time playing with friends and family, Rumah Kita allows the little patients to stay, study and play.

Those who have to stay at hospitals have no need to worry either. The little patients can study at Sekolah-ku, located near their wards in Cipto Mangunkusumo General Hospital, Dharmais Hospital and Fatmawati Hospital.

"Like I said, cancer may kill the children, but their spirit should not die. And this is just how we, parents, can help them," Ira said.

Neverending spirit is just what everyone can find in 11-year-old Sonia Rahayu, who has been suffering from bone and muscle cancer for two years.

"I missed my friends and school in Pandeglang [West Java]. I was absent for many days and skipped so many exams. But I think my teachers love me so much that they haven't expelled me yet," Sonia said, laughing.

"But that's fine. Here [in Rumah Kita], I can still study and have so many friends, too. And since I'm the oldest here, they have to listen to what I say," she said, seriously now, while still playing with Aisya.

A moment later, Sonia set out to prove the truth of her own words. She leaned toward Aisya, saying teasingly, "Now, you have to show us your fake eyeball."

As Aisya tried to push away Sonia's hands, laughter filled the house again, where not even illness can stop children from sharing their love and spirit.

Early detection can make the difference

It is never easy to treat children with cancer, nor is it easy detecting the disease.

Child cancer specialist Djajadiman Gatot said parents often had difficulty noticing the signs of cancer in their children, because, unlike adults, small kids tend not to complain about any pain or sickness they are enduring.

"That's why in most cases, the children come to the hospital when they are already at stage three or four," said Djajadiman, a doctor at Cipto Mangunkusumo General Hospital.

Leukemia, he said, is the most common type of cancer found in children, accounting for a third of the total number of cases. Other types of cancer affecting children include brain cancer, bone and muscle cancer, lymphoma (in the lymphatic system), retinoblastoma (eye cancer) and Wilms tumor (kidney cancer).

Although there is no exact figure on the incidence of cancer among Indonesian children, in

Greater Jakarta alone around 650 children are diagnosed with cancer each year, according to the Indonesian Children's Oncology Foundation.

Cipto Mangunkusumo General Hospital, for example, records around 130 to 150 new cases of child cancer each year, according to Djajadiman.

But cancers in children are more likely to be cured than those in adults, he added.

"Most cancer cases in adults have to do with external factors, like the condition of their surroundings. That makes them more difficult to handle," Djajadiman said.

Cancers in children, in the other hand, tend to be genetically caused.

"That's why they're more curable," Djajadiman said, adding, "around 70 percent of cancer cases in children can be cured."

The likelihood of curing a child of cancer, however, depends on how early the symptoms are detected.

"The earlier the cancer is detected, the greater the chance for the child to be cured because he or she can be provided with early medical treatment," Djajadiman said.

Ira Soelistyo, co-founder of the Care for Cancer Kids Indonesia Foundation, added that support and affection also greatly contribute to the healing process.

"From my experience, love and support can contribute some 40 percent to the child's recovery, while the rest goes to the medical treatment," Ira said.

But cancers in children are more likely to be cured than those in adults.

- JP/Dian Kuswandini

House offers healing for a heartbroken mother

The sun is finally shining again for Ingrid Lolita, after the death of her 10-year-old son. Where once spent her days at home alone, breaking down every time she saw a hospital, Ingrid has now found a new world to sustain her: Taking care of children with cancer.

By dedicating her life fully to the little patients at Rumah Kita, Ingrid said, the longing she had for her son, Aditya, had begun to fade away.

"Treating other kids with cancer here has healed the wound in my heart. It feels like I found what had been missing in my heart," the 56-year-old said.

Ingrid said the new episode of her life began after she had a recurring dream.

"For so many nights, after the death of my son in 2004, I had the same dream over and over again," Ingrid said. "In reality, I felt all alone because my son was the only one that I had in life. But strangely, in my dreams, I was surrounded by many children."

It was only after she met Ira Soelistyo, the founder of the Indonesian Care for Cancer Kids Foundation, that she understood the meaning of her dreams.

"I suddenly realized that there were other sick children who needed my care. My son might have gone, but I still have responsibilities to other kids," Ingrid said.

From the first moment she stepped foot in Rumah Kita and saw the faces of the children there, Ingrid felt she was seeing her son in each one.

"Now when I miss my son, all I have to do is look at the children's faces."

Not only has Ingrid found a remedy for her own pain in taking care of children with cancer, she is also finding pleasure in supporting kids' parents.

"Those parents come from many places across the country, but in Rumah Kita, they share the same hope of seeing their children as healthy as before," Ingrid said.

Eka Prihartini, 33, is one of the hopeful parents who found her new home in Rumah Kita.

"I often worried a lot when I was alone," said Eka, the mother of four-year-old Aisya Putri, who came all the way from Lampung. "But being here with so many friends who face similar problems really helped me out."

- JP/Dian Kuswandin