



RACHEL HOUSE

By Lynna Chandra

Rachel House was established as a not-for-profit organisation in late 2006 under the name of “Yayasan Rumah Rachel” in Indonesia, with the aim of bringing palliative care to children from poor families who had neither access to, nor could afford pain and symptom management during the final days of their lives.

Being the pioneering paediatric palliative care service established in Indonesia, Rachel House faced an uphill task in the early years; ranging from the absence of trained medical professionals (in palliative care), the absence of regulations that govern palliative care and the general lack of acceptance by the medical profession, to the general public’s total ignorance about palliative care.

With this as a backdrop, Rachel House started its long and at times, arduous journey to establish the first paediatric palliative care service in Indonesia.

Whilst a larger 60-bed hospice was in the original plan, we set ourselves an initial (and we thought, simpler) task of finding a location for a 10-bed inpatient hospice. This proved to be a bigger challenge than we had anticipated. Doors were slammed in our faces and leaders of communities mocked our plans to set up what they called a “death house” in their neighbourhood. Health regulators could not give us a definitive answer as to whether or not a hospice license could be issued for our

operations.

After a full year of disappointments and still without a site from which to begin the hospice, we took the risk and began the recruitment process in late 2007. In January 2008, we recruited a doctor experienced in hospital management, and by April 2008, we had found and recruited five nurses who were courageous enough to leave their jobs to join a new organisation without any track record.

The nurses were given the daunting task of writing Rachel House’s first Standard Operating Procedures with zero knowledge of palliative care. In July 2008, still without any success in finding a location for our inpatient facility, we launched our homecare operations and began providing palliative care to children with terminal cancer.

Desperate for guidance for our nurses, and in the absence of a role model and a qualified palliative care professional, we looked for assistance and found support from the palliative care community in Singapore. With the Singapore International Foundation’s (SIF) support, a two-year programme was quickly assembled in late 2008 to provide paediatric palliative care training to Rachel House’s medical team and the Dharmais Cancer Centre with which we had begun to collaborate.

Mistakes were many in the beginning

A 60-bed hospice was originally planned in

order to meet an anticipated huge demand. As soon as the services were launched in 2008, we quickly saw that children preferred to spend their last days at home, in the security of their own environment and surrounded by their immediate and extended family. This is the case, no matter how basic their homes may be. And often, the fact that their parents have to continue to work made it impossible for these children to be admitted to an inpatient care facility. This meant that the three-bed inpatient facility we started in December 2008 remained empty most of the time, while demand for homecare services grew steadily.

In the beginning, our homecare services covered the entire Jakarta and its surrounding areas, which meant that most of our nurses’ time was spent in the car travelling to patients. In the end, we found that we had to learn to say “no” to some patients and carved out coverage areas to ensure better use of our nurses’ time.

With Jakarta’s horrendous traffic jams, our nurses were spending a great amount of their time in the car travelling to patients, even with the implementation of restricted coverage areas. This led us to finally decide on motorcycles as the mode of transport for our nurses – which cut down on travel time immensely.

The lessons never stopped. The desperate situations in which we invariably find the children have never ceased to shock us into action. As our team grew comfortable with their

learning curve in providing palliative care to children with terminal cancers, we embarked on providing care to children with HIV in late 2009. Here, we found ourselves once again groping in the dark, once again pioneering the way with no role model.

So, this is where we are today, reaching out for and seeking guidance on the role of palliative care for children with HIV/AIDS – to answer questions such as: What should our admission criteria be? When should these children be referred to us? What is the nutritional care necessary for these children when faced with chronic diarrhoea and malnutrition? Should we set up a separate team to provide care to children with HIV/AIDS, as the care needed differs quite considerably?

In children with HIV, where in most cases one or both parents have perished and where stigma and discrimination bring isolation, we find ourselves face to face finally with the vision that launched Rachel House – that no child deserves to die alone, in pain and unloved.

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Lynna Chandra is an ex-investment banker who started Rachel House in memory of her friend Rachel Clayton who fought a brave fight against cancer.



▲ Launch of the SIF program on 21 April 2009 in Jakarta, attended by the Singapore Ambassador and his wife, His Excellency Ashok Mirpuri and wife (Gouri)

Calling for volunteers! Those interested to find out more about Rachel House and support its activities through volunteering or donating, please email Lynna at info@rachel-house.org