

## Hidden lives of children with genetic conditions highlighted in World Day Report

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Feature | People and places



Children with genetic conditions belong in palliative care programmes. In this article, Dr Chong from StarPALS in Singapore, explains that these children and their families deserve the compassionate and comprehensive care that palliative care can provide.

Taken from the World Hospice and Palliative Care Day report, available to download from the [Worldwide Hospice Palliative Care Alliance website](#), Dr Poh Heng Chong, Medical Director of StarPALS, talks about the hidden children with genetic conditions.

"Genetic conditions, particularly when severe, can wreak havoc not only to the well-being of the young child but also almost every other member of the family, with uncertain, yet ominous implications on subsequent pregnancies," says Dr Chong.

"The tremendous burden is multiplied when more than one child is affected by the same syndrome. These families certainly deserve the comprehensive and compassionate support that palliative care can provide, to make every moment meaningful and worthwhile."

### Genetic conditions

- 2-3% of births result in babies with either congenital or genetically-determined abnormalities.
- Duchenne muscular dystrophy affects approximately 1 in every 3,500 male births in the UK.
- Many children, particularly in low-resource settings, will never receive a definitive diagnosis of their condition.
- Children and young people with genetic disorders are living longer thus posing a challenge as they transition into adult palliative care services.

In Singapore, support is provided to these children by a children's palliative care organisation called StarPALS. [StarPALS](#) (Paediatric Advance Life Support) is a dedicated children's palliative care service that supports children living with life limiting conditions and their families in Singapore. Funded by a government grant for four years, StarPALS aims to improve the lives of families who struggle with one of life's most difficult challenges using a novel approach. Different components of its comprehensive service elements are customised to meet often myriad and unique needs.

Dr Chong says that when the child has a genetic condition (like 7 year old Vera who has Trisomy 18, pictured here with her mom) the disease trajectory can be unpredictable. However, parallel planning ensures that one is always prepared for the worst, while living life to the fullest in the present. In these situations, provision for respite becomes very important.

#### **Providing respite**

The often single caregiver is able to access breaks when we send in Medi Minders. These are trained volunteers who help look after the child for a few hours such that the tired caregiver can rest, even for a moment. Vera enjoys sessions with our music therapist who helps connect the whole family together with songs. Melodies would be created by everyone at home, who are encouraged to grab an instrument each like players in a symphony! This way, our young patient not only gets her own special time, the whole family is drawn even closer together, sealing memories of joyful merrymaking.

StarPALS hope to continue improving the quality of life of all our clients like Vera but would need to be able to demonstrate meaningful yet robust outcomes that make sense to funders and more importantly, policy makers, so that children like Vera no longer have to live in the shadows but emerge stronger and happier.

*This article was first published as a case study in the report: [Hidden Lives, Hidden Patients](#), commissioned for World Hospice and Palliative Care Day 2015. The report can be found on the [Worldwide Hospice Palliative Care Alliance website](#) and will be officially launched on 10 October 2015 as part of the World Hospice and Palliative Care Day celebrations. To find out more or to register an event for the Day, please visit the [World Hospice and Palliative Care Day webpage](#).*

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