

The Story of Little Rose

January 2019 marks one year since HOPE Cape Town's Occupational Therapist, Robyn Meissner, started seeing little Rose. Born one month premature and weighing 1.62 kg at birth, Rose tested positive for HIV just after birth and was being seen at the paediatric antiretroviral (ARV) clinic in TC Newman Community Health Centre situated in Paarl, in the Western Cape. Soon after she was first seen, her parents failed to bring her back to the clinic for follow-up management and continued ARV dispensing.

Rose was finally picked up in the health system again when she was diagnosed with pulmonary Tuberculosis (TB) and malnutrition in December 2017. She was admitted to a specialised TB hospital and re-joined the ARV clinic at TC Newman. It is thought that her defaulting ARVs may have been due to her parents' lack of knowledge of HIV and the importance of taking ARV treatments correctly.

When Robyn performed her initial evaluation of Rose, she was 2 years and 8 months of age. Rose was not able to walk or talk yet, and she was functioning on a one year old developmental level (a delay of 18 months) across all developmental areas. Initially, Rose was very unhappy and very sick, she cried a lot when any medical professional examined her. It took about two visits with Robyn before Rose warmed up and a bond began to grow.

Both of Rose's parents are involved in her life but she was separated from her parents while she had to stay in hospital and only saw them when they visited on weekends or brought her for her ARV appointments at the clinic (once a month). This has a significant impact on Rose's progress, since most of the nurses at the TB Hospital spoke Afrikaans and Rose was Xhosa. The hospital also did not have any specialised paediatric services and so very little stimulation and play opportunities were available.

Robyn started providing occupational therapy with little Rose, which included play activities involving walking, such as playing with balls and balloons. Other play activities (such as drawing, reading books, building with blocks and cups) were part of Rose's occupational therapy plan to stimulate other developmental areas such as speech and communication, fine motor skills and independence in self-care tasks.

Most importantly -Rose's parents received guidance and resources to stimulate Rose's development. In order to ensure continuous development of Rose, it was necessary to equip and empower her parents with the skills and knowledge regarding her development. Child development can only be improved on with continuous interaction and stimulation in all aspects and tasks of a child's day –so as primary caregivers, they had to understand their roles well. Her doctors at the clinic and HOPE Cape Town's community health workers at the clinic –Sheila Samuels and Nomsa Nqwita helped her parents to understand the importance of adhering to her prescribed ARV treatment.

And where is little Rose today?

Rose started walking in April 2018, after four months of therapy with Robyn Meissner. Rose was finally discharged from the TB hospital in October 2018. She has also started receiving speech therapy, in order to improve her speech and develop better communication skills she can use with her parents and friends. From her development being delayed 18 months, Rose's development is now only delayed by about 8 months in some areas. Her parents are also more settled in knowing their roles and better equipped to cater for her needs. Her parents bring her regularly to the clinic to receive her treatment as prescribed.

Little Rose's story is a great example of the significant importance of home stimulation in a child's development and the difference it makes when the parents recognise their responsibilities, are well-educated and understand their ARV treatments. This story is also a great example of the multi-disciplinary team at work to provide holistic care to save and improve a child's (and their family's) life.

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