

A Sunshine Girl



"I feel like a baby now," RX said, her cheeks flushed. "My parents now treat me like a baby. Mum, in particular, is always on my side," she smiled. She seemed to be longing for her mother's attention. "I feel sorry for my brother," she grinned again, "because now I have both of them to myself," she admitted without hesitation.

RX was born into a middle-class family with two children. Her brother has a congenital brain condition that has caused him to depend on others for most of his daily activities since he was a child. The mother is the breadwinner of the family, while the father is the main caregiver for their son at home.

She was a typical 13-year-old girl who enjoyed singing, listening to Chinese pop songs, watching films and drawing comics. She awoke with a severe headache that lasted many days. Her parents brought her to the hospital's emergency room when she began vomiting on a regular basis. That's when they found out the bad news. Their "healthy" child became dependent due to a rare right thalamic tumour that paralyzed her on the left side. Because the cancer is at a sensitive location, surgical removal is not an option.

RX stayed at a halfway home for several weeks before completing her radiotherapy treatment. Her mother relocated the family from the outskirts of KL to their former flat house near the hospital for cancer treatment during this time. She responded well to radiotherapy and improved significantly. She was able to walk again by using a walking stick.

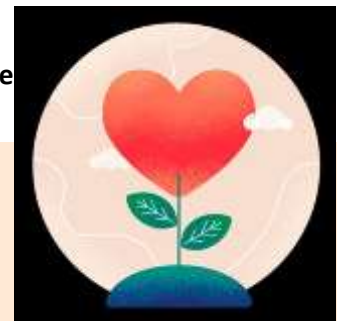
Despite her excitement of being a "baby", she occasionally wishes she could be an adult. She expressed a desire to take her family to the movies. She planned to pay for them with her own money. She did not, however, have enough money.

"Every Chinese New Year, we'd go to the movies and watch Chinese New Year films. We haven't done this since the covid epidemic began," her face was disappointed. She seemed to value the time she spent with her small family. "How about writing an article for the MAPPAC Newsletter?" We'll give you a fee for your article." We encouraged her. She instantly began writing an article about her illness.

**I've been moved by this girl's determination more than once
She never showed signs of frustration or giving up during
her cancer fighting journey.**

"My father is always ready to assist me. But I'd rather do it on my own." Despite being weak on one side, she tried to resume her daily routine. Every time she stepped into the clinic with her limping gait or was wheeled in, she brought a joyful tone and a bright grin with her. Her eyes were generally bright and glistening. She is a SUNSHINE GIRL, bringing warmth and cheers to everyone.

"I wish I could be an adult and earn enough money to support my parents." It saddened me to see her so upbeat about her future. She can't wait to be a working adult who can help her parents overcome financial challenges.



Spirit to keep going

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Her "world" in the sand play was surrounded by her family members - her parents and her brother. The other items she added in her "world" were her favourite soda and chocolate cake. In that session, we discussed death. "I want my parents and my brother at my side." "I want it to be quiet, at home, with calm music playing in the background."

Her cancer relapsed exactly one year later, and she is currently in the terminal stage. I paid her a visit at their place 2 weeks ago. She was in a loaned hospital bed, looking frail but yet smiling at me. A queen size bed next to her's took up almost all of the available space in the small room.

"Ever since she returned from the hospital, she has insisted that we all sleep in the same room." Her mother explained. She was in the hospital for approximately a week before learning that the disease had relapsed. We exchanged glances and seemed to comprehend what RX was implying. "Are you scared?" She lifted her right hand, indicating "not really" in her usual nonchalant way.

My heart sunk as I observed this sunshine girl gradually lose her brightness. I frequently thought of her after my return from KL. Remember her sparkling smiles, not this girl's progressively withering self, I told myself, Spirituality is the most valuable thing I learned from her. What is meaningful to her is the interpretation of her spirituality. What is significant is that she can do things on her own and she is able to do something for her family. Even as she nears the end of her life, she values the ability to remain with her family rather than being separated in a hospital room.

**Death and dying, with the right support, can be a spiritual, dignified, and peaceful experience.
May everyone of us involved in this field of work feel proud to be a part of this experience.**

I do and I know many of us will!



Dr Ng Su Fang has also been actively involved in the various MAPPAC fund raising events. You will get to read more of her when she takes to the helm again as the Organising Chairperson of the Malaysian Children Hospice Festival (MCHF), a fund raising event tentatively scheduled for May 2024



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