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My child has cancer: How families strive to stay together and become stronger



Myra Aqisha Mahadir (centre), who has Down syndrome, is also a cancer survivor. ST PHOTO: VENESSA LEE



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SINGAPORE – The whole family is affected by the seismic shock of a child’s cancer diagnosis.

Family dynamics change and relationships are strained when a child has cancer, especially when hospital stays can last for weeks at a time, says Ms Lesli Berggren, founder of Love, Nils, a Singapore charity which supports children with cancer and their families here.

“There are many facts about cancer that people don’t understand that can upend daily routines. It’s a 24-hour job,” says the American, who lost her 14-year-old child to cancer. She has since relocated back to the United States.

For instance, once a child begins treatment, he or she will most likely be put on a neutropenic diet – which eliminates raw or uncooked food – to reduce the risk of getting an infection.

“Your home cooking and kitchen will change completely,” says Ms Berggren, speaking to The Straits Times from Colorado in the US.

Because cancer can be so isolating, she advocates keeping things as normal as possible, whether it is playing games together or dispensing hugs liberally.

Try as many families might to give their cancer-stricken kids a normal childhood, it is difficult, notes Ms Norhashimah Kamarudin, manager at cancer support charity Ain Society.

“Girls who lose their hair, for example, may struggle with their body image. Child cancer patients have to take time to recover. They can enjoy their childhood on their own terms,” she says.

According to the National Registry of Diseases Office’s Singapore Cancer Registry, the incidence rate of childhood cancer among children aged zero to 19 years has remained stable at about 17 per 100,000 Singapore residents from 2013 to 2021, says a Ministry of Health spokesman.

During this time, the three most common types of childhood cancer were leukaemias, lymphomas, and tumours of the central nervous system and brain. These accounted for about 54 per cent of all childhood cancers diagnosed during the period.

In the lead-up to Childhood Cancer Awareness Month in September, The Straits Times speaks to families with child cancer survivors about the fond childhood memories they created, amid the ravages of disease.

So many miracles: Jennifer Yeo



Ms Jennifer Yeo, founder of Viva Foundation for Children with Cancer with her youngest child Frederick. PHOTO: COURTESY OF JENNIFER YEO

Half of the immediate, six-member family of Singapore's former foreign minister George Yeo have had cancer.

His wife, Mrs Jennifer Yeo, had a rare form of nose cancer with a high mortality rate in 2017. In 2013, their second child, Edward, now 33, had a seminoma surgically removed from his chest.

Earlier, in 1996, the youngest of their four children, Frederick, was diagnosed with acute lymphoblastic leukaemia at the age of three. He went on to suffer a relapse at age 10.

Frederick, now 29 and a junior doctor in Britain, had a chance of survival of less than 10 per cent as a child cancer patient, even with the bone marrow transplant he underwent.

Mrs Yeo, 65, who founded Viva Foundation for Children with Cancer in 2006 to help raise cure rates, says her Catholic faith sustained her through these ordeals.

She had been certain she would lose Frederick, and was later close to dying herself.

She says: “There have been so many miracles in one family. Through it all, I’ve learnt to live with the unknown. I learnt to put my trust in God.”

Viva Foundation will hold a free fund-raising concert (tinyurl.com/y2y6veb2) on Aug 27 at the Singapore Botanic Gardens. It will feature Fivera, a Thai pop-opera group, and Joanna Ampil, a performer from the Philippines who is known for playing the central role of Kim in the Miss Saigon musical.

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The foundation also operates in Hong Kong and China, where it has supported a large-scale, 13,000-strong study in child cancer for the past nine years, producing 14 papers in peer-reviewed journals, says Mrs Yeo.

She plans to launch a chapter of Viva in Indonesia soon.

On Aug 30, the National University of Singapore’s medical school will launch the George and Jennifer Yeo Professorship in Paediatric Oncology, as a tribute to their contributions to Singapore and dedication towards advancing the field.

Mrs Yeo, who is now a senior consultant in a law firm, urges the parents of child cancer patients not to give up.

“As parents, we feel very helpless, but there’s a lot you can do to keep the child’s spirits up and keep encouraging him or her,” she says.

“When Freddy was sick, I loved him like he was my only child. But I realised I loved them 400 per cent, instead of 25 per cent each. Love multiplies.”

Leaving their jobs for their child with cancer



Ms Jocelyn Chong and her husband Mr Raymond Lim with their children Noelle (left) and Harper. ST PHOTO: DESMOND FOO

When Ms Jocelyn Chong's daughter Harper was diagnosed with cancer at four months old, the housewife's main social interaction was with hospital nurses.

Harper, now nine, had been given a month to live when she was diagnosed with acute lymphoblastic leukaemia. It was discovered after the infant had a high fever and multiple bouts of diarrhoea within a day, prompting a hospital visit.

Ms Chong, 42, recalls: "Harper was our first child, so my husband and I decided to quit our jobs.

"We didn't want to miss her growth, she has lost a childhood and faced different kinds of pain and discomfort. As her parents, we tried our best to accompany her, we want to give her all of our love."

She left her accountant job and her spouse, Mr Raymond Lim, 43, quit his role as a project coordinator in the construction industry.

He set up his own handyman business, so he could manage his time and care for Harper together with his wife. He is now a warehouse supervisor, and they have a younger daughter, Noelle, aged seven.

During the first six months of intensive cancer treatment, Ms Chong spent most of her daytime hours with her baby in the ward. Her only adult conversations were with nurses who sometimes kept an eye on Harper while she stole out for a brisk walk.

Mr Lim bought meals for his wife and took over at night. The couple spent an hour together each day during dinner time at the hospital room.

Toys, such as a Minnie Mouse plush toy, gave her baby some comfort then. Ms Chong has photographs of Harper clutching it, which attached to a hospital tube.



Harper Lim was diagnosed with cancer at four months old and had been given only a month to live. She still has the Minnie Mouse toy that comforted her during her cancer treatment. ST PHOTO: DESMOND FOO

At age three, Harper’s cancer went into remission. But for years afterwards, she would recoil when multiple people entered a lift after her, a possible throwback to the time when she was constantly surrounded by doctors and nurses in confined spaces, says Ms Chong.

Now a Primary 2 pupil, Harper, who deferred school for a year, has learnt to socialise more after art therapy sessions with cancer support charity Love, Nils.

Her mother, though, has never got over her dread and phobia of those cancer-stricken years.

“I’ve changed a lot since then. I had to be calm and positive, and control my temper, as I did not want to be a bad influence on Harper then. She could sense my emotions,” she reflects.

“Now, we keep moving forward.”

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Cancer survivor with Down syndrome reveals fighting spirit



Myra Aqisha Mahadir with her parents Ms Arwati Alip and Mr Mahadir Jasini, and older brothers (from left) Muhammad Alfian Mahadir, Muhammad Aydan Mahadir and Muhammad Adrian Mahadir. ST PHOTO: VENESSA LEE

When Ms Arwati Alip was pregnant with her fourth child, she was elated to be expecting a girl after three boys.

But she was blindsided when Myra Aqisha Mahadir was born. Myra, now four, has Down syndrome, which no prenatal scans had picked up.

Ms Arwati, 45, and her husband Mahadir Jasini, 44, who both work in the freight forwarding industry, fretted over what their daughter's future would look like.

That flew out of the window when a greater shock was sprung upon them. Myra was diagnosed with acute myeloid leukaemia when she was 1½ years old, following a routine blood test.

Ms Arwati says: "She was playing well at home and did not seem sick at all. There was no fever, no lethargy. She was so active."

The only tell-tale signs were tiny, red, measles-like spots that surfaced now and then on Myra's body. They later found out that it was a common skin condition associated with leukaemia.

Ms Arwati shed copious tears during the six months of chemotherapy in 2021, whenever Myra was whisked away for treatment for long periods.

As she accompanied her daughter, she missed her sons, now aged 16, 14 and six. Her youngest son, Muhammad Aydan Mahadir, was only four then.

She spent Monday to Friday evenings in hospital with Myra, while her husband took over from Friday night till Sunday noon.



Myra Aqisha Mahadir with her parents Ms Arwati Alip and Mr Mahadir Jasini. ST PHOTO: VENESSA LEE

“We had only five minutes to talk in person every week” during the changeover at the hospital, she recounts.

“People might be thinking that we are such a strong mummy and daddy, but I cried almost every day. We’re thankful that we’re still together.”

She tried to take the boys out to their usual haunts – McDonald’s and the swimming pool – on weekends, putting on a cheerful front for them, though she was pierced at the sight of whole and happy families out and about.

After Myra recovered when she was about two years old, Ms Arwati resolved to spend more time with all of her children. “I don’t want to lose a single moment with them,” says the customer service executive.

She remembers how Myra's steely character came to the fore during her chemotherapy. The toddler would fight the sedatives given to her, looking groggy rather than falling asleep. She stopped crying after the initial treatments.

Now, Myra is a cheeky girl who loves to colour and draw. Ms Arwati says fondly: "She's the warrior in the family."

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5 tips for parents

Here are tips for parents dealing with their child's cancer journey.

1. Take extensive notes

American Lesli Berggren founded Love, Nils, a Singapore-registered cancer support charity, after her son Nils died at 14. In 2012, he was diagnosed with stage 4 lymphoma cancer at age 13 at National University Hospital.

The Texan spent 1½ years navigating her son's cancer, in and out of hospitals in Singapore and Seattle. She relocated to Singapore in 1998 and moved back to the United States in 2022.

Ms Berggren, who also has a daughter Claire, Nils' twin, will be in Singapore for Love, Nils' annual gala (bit.ly/LN-gala23) on Sept 23 at the Shangri-La Singapore to mark Childhood Cancer Awareness Month and raise funds for children with cancer and their families.

She says: "Managing hospital visits and medical instructions is incredibly stressful. It is like learning a new language and living in a new city. Everything is new. The best first tip is to have a notebook and write everything down."

She had to consult her notes as she was asked many times during Nils' treatment when a procedure was done, what his reaction was, how often the medicines were distributed, as well as dates and times.

If another person can be with you at doctor consultations, that would be helpful, she adds, since this second person may ask questions that do not occur to you.

2. Retain familiar routines

"Helping your child have a normal childhood as much as possible helps him or her emotionally, mentally and physically," says Ms Berggren.

"Reach out to the child's school and ask for support from his or her school friends and teachers."

She did this with the school Nils attended in Singapore, arranging for some friends and favourite teachers to visit him at home. She also arranged for a tutor to help him stay engaged and keep up with his schoolwork.

She adds: “Although many children with cancer cope well over time, your child may sometimes feel anxious, sad, stressed, scared or withdrawn. Talk with your child about what he or she is feeling and help find ways to cope. Your child can meet a child-life specialist or psychologist about feelings that don’t have easy solutions or seem to worsen over time.

“Your child can feel your emotions. If you often feel sad or anxious, talk with your doctor and child’s healthcare team, so you can manage these emotions. Keep in mind that if you often hide your feelings, your child may also hide his or her feelings from you.

“Dream of the future with your child. Make plans with him or her. For instance, my son loved hiking. We planned an entire trip to take a camper van to go camping. We wrote a checklist of what we needed, where we would go. I made a tent out of sheets in the hospital bed, filled with a torch, hiking maps and more.”

3. Take care of other family members and yourself

Ms Liow Hwee Hsiang, principal child-life therapist, Children’s Cancer Foundation, says: “Cancer within the family affects siblings too. Spending just a little time each day to lend an ear, express care and show affection can make a significant difference. Keeping them informed and engaged, even in minor ways, in the care of the ill child is also beneficial.

“Keeping children with cancer informed about upcoming events or developments is essential, as uncertainty can be more daunting for them.

“When confronted with cancer within the family, caregivers often tend to neglect their own needs. However, it’s crucial to carve out time for yourself to process your feelings, engage in relaxation, rest and maintain a healthy diet. By doing so, you’ll have more energy to be present for your child, allowing him or her to feel your full support.”

4. Pack and be prepared

Ms Berggren says: “Being prepared makes extended hospital stays easier. Patients often need to stay in the hospital for weeks or months at a time.”

She advises packing a suitcase. Include pyjamas, slippers, toiletries, comfortable clothing, a sweater, a water bottle, snacks, teas, pillow, books and your laptop. Earplugs and eye shades help when nurses come into the room to check the child’s monitors throughout the night.

“But, more importantly, pack a suitcase for your child. Include his or her favourite pyjamas, sweater, beanie cap, stuffed animal and pillows. Take along games, toys, playing cards, books, art and crafts, and family photos to help make your child feel more at home.”

5. Engage with people on your own terms

Ms Berggren says: “People will ask for updates. I didn’t have the time to reply to individuals. Instead, I posted updates on social media or wrote letters about what was happening and sent one e-mail to all my friends and family weekly or monthly. Many people use platforms like CaringBridge to share updates and ask for support.”

She says: “Unsolicited advice will always come. You can reply with, ‘I’ll think about that’, ‘That’s an interesting opinion, but I prefer to do it this way’, ‘Good idea’, or ‘That’s not in line with my values.’”

She adds: “My most challenging conversations were when people would compare their situation with mine, or tell me about their trauma or cancer death. One of the most straightforward tips I can give anyone reaching out to support a caregiver or cancer patient is listening.”

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