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Baby & Child

Children and cancer: change of fortune

While it is one of a parent's worst nightmares to hear the 'C' word, cancer is no longer the death sentence it once was. Treatment for childhood cancers has improved so much that 80 per cent of patients will survive, compared with 20 per cent 30 years ago. Judith Tan and Shefali Srinivas take you from diagnosis to life after treatment.

Madam Pinky Lan thought her 21-month-old toddler had a bad case of 'wind' when his tummy began bloating up.

A visit to the general physician and some medication didn't get rid of it, so she took Terry to a specialist for a second opinion.

The paediatrician referred the baby to Singapore General Hospital, where he was diagnosed with leukaemia.

That was in 1996.

Like every parent whose child is diagnosed with the dread disease, Madam Lan's world instantly crumbled.

Would her only son die? Why Terry? What had she done wrong? What should they do now?

But before the questions could take over her mind, the hospital's cancer management team swung into action.

At the next visit, a few days later, Madam Lan and her husband met the medical team made up of the doctors and nurses who would treat and care for her child.

'I was expecting my second child at that time and you can imagine how very confused I was when Terry was diagnosed. When I was first told the bad news, my mind went blank. I didn't know what I was supposed to do next. The doctors and nurses were nice enough to explain things. It helped,' she said.

Treatment for childhood cancers today is a far cry from what it was just a few decades ago, when being diagnosed with a malignancy meant you had a dismal chance of survival of 20 per cent.

Today, some 80 per cent of children who contract childhood cancers such as acute leukaemia, lymphoma, kidney cancer and germ cell cancer will survive, because of advancements in technology, drug therapy and treatment methods.

Doctors now know so much about tumours and their subtypes, that they can decide if the best treatment should be surgery, chemotherapy, radiation therapy or a combination of the three.

According to Dr Tan Ah Moy, head and senior consultant of the paediatric haematology-oncology service at KK Women's and Children's Hospital, cancer care has become more multifaceted in recent years, drawing together the different modalities and approaches from the outset.

'One of the major advances in the last two decades is a more intensive chemotherapy regime and a multidisciplinary approach to treating the child. This means the child is treated by a team including a surgeon, oncologist and radiation oncologist who do their best for the child,' Dr Tan said.

Clinical treatment is not the only thing that has improved. Cancer management is now much more holistic. Aside from the medical specialists, nurses, psychologists and social workers are included in the care to ensure that the patient and parents have the appropriate support for their needs.

'We look into psychosocial and financial support for parents. We have social workers to give their

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support in terms of play therapy, psychological support for both the child and family, in any aspect. Sometimes, it may be getting back to school or making up missed lessons, just helping them get back to life again after this treatment,' Dr Tan said.

100 KIDS EACH YEAR

Each year, about 90 to 100 new cases of cancer are detected in children under 15 years here, which makes up only 1 per cent of all cancer cases in Singapore.

Dr Tan, who has worked in this field for the last 20 years, said that it can sometimes be difficult for parents to accept the diagnosis of cancer. She said: 'Sometimes, people cannot believe that it is possible for a child to get cancer.'

Some parents stay in denial for a long time.

'They go looking for alternative treatments and come back to us when the child gets more sickly. We lose precious time in which we could have intervened. That makes me very sad,' she said.

Parents interviewed by Mind Your Body said however, that they went quickly from shock and distress, to wanting to find out everything they could so that they could get the best treatment for their children.

Mr Kamsani Raman's daughter, Noor Shaqinah, was diagnosed with leukaemia more than three years ago. She was then eight years old.

'I can still remember that day very clearly. It was Nov 26, 2001. It is a date I would not be able to erase from my mind,' he said.

That evening he went into cyberspace.

'I wanted to know what the symptoms were, why it was not detected earlier and what the available treatments were,' said the 42-year-old security officer with a hotel.

The Internet has become a lifeline for almost everyone who suffers from a serious illness, and parents whose children have cancer are no exception.

When her daughter Rachel was diagnosed with Ewing's sarcoma in 1999, Mrs Bessie Foo turned to the Internet for more information on this rare form of bone cancer.

'I found out that Ewing's sarcoma is usually found in children and young adults. It usually happens between the ages of 10 and 20 and is less common in children under five or in adults over 30,' she said.

She also learnt that the cancer can occur in any bone in the body and the most common sites are the pelvis, thigh, lower leg, upper arm and rib.

Mrs Foo believes that her research on the Internet saved Rachel's arm from being amputated.

'It was from the Internet that I learnt about the different treatments and protocols available in different parts of the world and that the treatment, in Rachel's case, needn't involve amputation of her arm,' she said.

Mrs Foo said it was also through the Internet that she discovered one of four specialists in the world who treat this kind of cancer in children was right here in Singapore.

Professor Robert Pho, who was practising at the National University Hospital, is now Rachel's doctor.

Sometimes the information is only wisdom on hindsight, and cold comfort to parents.

In his trawling for information, Mr Kamsani found that one of the symptoms of leukaemia was junior rheumatoid arthritis, something which Noor Shaqinah, who prefers to be called Aisha, was diagnosed with when she was seven.

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'If only we had known earlier,' he said.

KEEP KIDS IN LOOP

It's not just parents who need to know about cancer.

While children may have been left out of the loop years ago - in the belief that they should be kept happy and not know how serious their condition was - many parents and doctors now tell the young patient.

And young as they were, all three knew when they were told - Aisha, Rachel and Terry, when he could understand - that something serious and terrible had happened to them.

Rachel said: 'I wanted to know as I was the one going through the chemo and I was the one being treated.'

Rachel's parents say their daughter was extraordinarily strong and this helped them to pull themselves along.

'I never thought I was going to die,' said the cheerful 16-year-old. 'I just concentrated on getting well and perhaps getting a pet dog. I had been asking my parents for one since I was little.'

When her hair fell out because of treatment, she even enjoyed pulling it out.

Yet her parents knew that she was in enormous pain.

Her shoulder blade had to be removed and her arm reattached to her collar bone. Not only did this mean weeks of rehabilitation, it also took a year for the wound on her back to heal, and it would alternate between hurting and itching.

Yet today, it is nearly impossible to tell which arm is the one that had to be operated on. Tell her this, and it makes her beam.

'This means I'm doing a great job!' she grins.

It was her right arm - which she used to great effect last year in the O levels, gaining an aggregate score of 11 for her first language and five other subjects.

Rachel's response to her illness heartened those around her, but not every child will be like that.

Children do understand that something 'bad' has happened to them but need to be told that they are not to blame for their condition.

Studies suggest that parents should explain the course of treatment and familiarise the child with the hospital environment.

Once the nurses and doctors become actual people, the child finds it easier to cope with the demands of managing the disease.

Explaining cancer and chemotherapy to an adult is difficult enough but telling a child can be heartbreaking.

Parents talk about the pain of dealing with a scared child and questions like, 'Am I going to die?' or 'Will I ever grow up?'

One way of dealing that parents have found helpful is to include the child in conversations with the doctor.

Madam Lan said that her son Terry, now 11, was an active participant in discussions about the management of his cancer, which has flared on and off in the last nine years.

'Terry would tell the doctors to speak to him as well and not just to me as he was the one being prodded and poked,' she said.

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Such sentiments were also shared by the Foos.

Mrs Foo said at the initial stages when Rachel was first diagnosed and admitted, the doctor in charge spoke only to the adults and ignored the child completely.

'I wasn't comfortable with the whole arrangement. I felt it was not right for him to have done that. After all, she was the one who was the one who was sick and needed to know what was wrong with her,' Mrs Foo said.

There was a sea change when they turned to Prof Pho.

'Prof Pho was really child-friendly. He included Rachel in all our discussions. She was told about the operation to remove her shoulder blade, her chemotherapy and how aggressive it was going to be. In a way, it helped her to accept her situation,' Mrs Foo said.

The Foos found they had to be adaptable during the months that Rachel had to undergo treatment.

'One of the side effects for her was she didn't like the smell of cooking and lost her appetite for food. The only food she would keep down was McDonald's burgers. I know it is unorthodox but we had to feed her fast food to keep her strength up,' said Mrs Foo, who gave up her job to take care of Rachel when she had chemotherapy.

It's not just the months or years of treatment that children need to get through. Recovery can often be difficult too.

Apart from coping with the side effects, there is the matter of going back to school. Not only do the children fall behind in their schoolwork, they sometimes face ridicule from peers too.

Both Terry and Aisha recall how their classmates called them 'botak' (Malay for baldy).

To combat this problem, social workers sometimes try and arrange to visit the school before the child returns. They talk to the child's peers and sensitise them to their classmate's plight and teach them not to tease or otherwise provoke their friend.

SUPPORT PARENTS

A social worker from the Children's Cancer Foundation (CCF) said that when parents are told of the diagnosis, they are often in denial, get angry or become really depressed.

Hospitals provide a social worker or psychologist whom parents can turn to. There are also several private foundations which offer support.

'We just lend a shoulder to cry on, listen while they vent but don't challenge them,' said the CCF social worker.

'Once they calm down, we offer them emotional support by setting up meetings with the doctors, introducing other parents who are also in the same situation and should they be in financial difficulties, offer them different avenues,' she said.

Help is also given to young patients.

The CCF introduces play and art therapies to help children understand and become less afraid of their illness.

'For the younger children, we use teddy bears and syringes and allow them to poke the bears. This way, we are able to explain chemotherapy to them. The older children are usually put through art and craft therapy to help them forget their illness, at least for a while,' she said.

A major issue is financial support. Aside from being expensive, cancer treatment can be protracted, and one parent often takes unpaid time off work to care for the child.

Social workers will go through with them the various avenues of financing, from what can be withdrawn from Medisave and MediShield, to the funds available from voluntary welfare organisations. Both Madam Lan and Mrs Foo were lucky - they had stout support from their

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families.

Madam Lan's parents helped to look after her two younger daughters while she camped out at the hospital during Terry's treatments.

'And when my Medisave and savings ran out, my sister-in-law used her Medisave to foot Terry's hospital bills. I am grateful for that,' she said.

Mrs Foo's mother cooked special meals for Rachel when she was undergoing her chemotherapy, to give her extra nourishment to endure the harsh treatment.

'I gave up my career to stay home with Rachel, while her father concentrated on bringing home the bacon. We were very focused on getting her health back,' Mrs Foo said.

For Mr Kamsani, it was a different story. Family members quietly stayed away when they found out that Aisha was ill. He found solace among other parents in a similar plight.

'They rallied around me and my family and I am grateful for that,' he said.

When Aisha was diagnosed, his wife had just given birth to their youngest daughter, Sabrina. She was so depressed by the news that she developed postnatal blues, and the couple had two older sons to look after.

'Life was pretty bad,' he recalled. 'It was with the help of these other parents that we were able to pull through. We call each other up to ensure we are okay and drop everything when one of us needs help. They are now my family.'

Cancer has such devastating impact, not only on patients, but also their families, that parents say that they could not have pulled through without the support of an extended network of doctors, nurses, family, friends and strangers who gave help and support.

New research has found that cancer does not doom youngsters to a miserable childhood. After treatment, many are just as happy and well-adjusted as those who never had the illness.

Rachel is testimony to this. She went back to school, garnered impressive O levels and is now waiting to register herself at LaSalle-SIA College of the Arts.

Aisha is in her first year of remission and has gone back to school.

Terry is still undergoing treatment. He has had a third relapse and is undergoing radiotherapy to control the spread of the cancer, but he too is back in school now.

Asked how she sees the future, Rachel said: 'I am trying to live my life as normally as I can. A day at a time. Every morning when I wake up, it is a real blessing.'

Next in our three-part fortnightly series on Children and Cancer: New breakthroughs in leukaemia

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