

Leukaemia patient Carli Highberger (right) and her brother Ethan at a photo shoot by Flashes of Hope, a non-profit organisation, at a hospital in Illinois. Young people living with chronic diseases display tremendous courage, having to go through treatment and hospital trips while their peers study and play.



# Young, sick and courageous

Three young people tell **Kasmiah Mustapha** how they are dealing with their chronic ailments

WHEN illness strikes young people, they will not be able to live life to the fullest. The illness will disrupt their lives and rob them off their dreams and future. But despite this, three young people are doing their best to overcome the obstacles and taking steps to lead a normal life.

## **NESAMALAR KANNAN, 18 (LEUKAEMIA PATIENT SINCE 11)**

She was too young to even understand what was happening. All she knew was that she had to stay in the hospital and could not go to school. She was told to follow doctors' orders and to take the medications. And she hated it.

At 11, Nesamalar was diagnosed with acute lymphoblastic leukaemia. She was suffering from prolonged fever and feeling dizzy all the time. One day, she fainted in the bathroom. When her parents took her to the clinic, the doctors told them that Nesamalar could be suffering from either dengue or leukaemia. She went to the hospital for further tests.

She recalls: "I remember lying on the hospital bed waiting for the results. The doctor came in and took my parents outside to talk to them. When they came back, my mother was crying while my father did not say a word. They told me I had to stay in the hospital. I thought it was a simple fever and that I would stay a week or two.

"I did know what was wrong with me. I remember having more tests done and it was then I knew that I was in trouble. The worst part was the bone marrow transplant. Mum was not allowed into

the operating theatre and I was alone. I was really scared."

The others in her ward were also suffering from leukaemia. She heard talks of people dying. The patient who shared the room with her also died.

### **FEAR AND ANGER**

At that time, Nesamalar felt scared, angry and sad but didn't know how to tell people about it. She was angry because she was sick. She was angry because she could not go to school. She hated staying in the hospital and having had to go through the treatments.

"But I didn't tell my parents how I felt. Instead I would take it out on my mother who was taking care of me at the hospital. I would get angry at her or refused to talk to her. I remember feeling guilty about it but I never apologised. Thinking about it now, I realised I was venting out my

frustration at her. But my mother never got angry with me. She would just let me be," she says.

"I had to take about 30 pills at one time. I couldn't walk. My mother had to help me to go to the bathroom. I felt I was a burden to my parents. I also felt guilty because my younger brother had to stay at home while my mum was in the hospital with me."

She was hospitalised for one year. Even after she was discharged, the doctors did not allow her to go to school yet for fear of infection since her immune system was low. She was isolated in a room for her UPSR examination.

Nesamalar goes for a check-up every six months. She is busy preparing for her STPM examination next month.

She says: "I am happy that I am healthy now, although I still worry that the cancer will come back. I am trying to lead a normal life although there are some things that I can no longer do and I have to avoid certain foods to make sure I don't catch infections easily."

*"I am trying to lead a normal life although there are some things that I can no longer do."*

*Nesamalar Kannan*

## **TEH SHENG RU, 25 (KIDNEY FAILURE SINCE 21)**

Every Tuesday and Thursday, you will find Teh at the National Kidney Foundation dialysis centre in Petaling Jaya, hooked to a machine via various tubes, for four hours.

Since his kidneys can no longer remove waste from his bloodstream and regulate water fluid levels in his body, this dialysis treatment is vital.

Teh was diagnosed with kidney problems when he was 10. During a bout of prolonged fever, the bacteria infected his kidneys. Tests showed that his kidneys were too small for his age. But since he felt fine, he was not worried.

Things took a turn for the worse when he turned 15. He suffered from prolonged fever again. A blood and urine check revealed that his kidneys were still smaller than normal. He was put on medication to control blood pressure for three years.

At that time, Teh was a Pahang state bowler as well as active in other sports too. He hated having to rely on medication so he stopped taking them.

This, however, caused his kidneys to fail completely when he was 21. He began to suffer from shortness of breath. He vomited after meals and he felt tired all the time.

He says: "The doctor told me my kidneys were damaged and that I had to start dialysis immediately. When I heard the news, I was depressed. I blamed myself. I regretted not taking my medication. My mindless action had put

*"I want to focus on living. I don't want to use my illness as an excuse."*

*Teh Sheng Ru*

me in this situation. I was also sad because I was an active person and with my condition, I could no longer enjoy the sport that I loved."

### **MAKING THE BEST**

Teh, a sales promoter, knows that nothing will make his kidneys function again. Initially, he did not tell his parents about his condition but, determined to make the best of the situation, he had never missed a dialysis treatment.

He is on a kidney transplant list, but it can take years before he finally finds a match.

"I do not want to ask my parents or family members to donate their kidney. I do not want to burden them. Of course, I want a transplant so that I don't have to depend on the machine anymore. But I can still live with dialysis. If I have to do dialysis for the rest of my life, it is all right with me," he says.

"I want to focus on living. I want to make myself happy every day. I don't want to use my illness as an excuse. There are things that I can no longer do like sports or carry heavy things but I can still work. There are others who are in worse conditions."

Teh advises other young kidney patients not to give up too. He says they should stop thinking that they are sick all the time and find ways to work around it instead.

"It may not be easy initially but you should be able to live your life like other people. I don't feel any different from healthy people. Having a chronic illness doesn't mean you should stop doing things you like. I will do anything to fight my illness. Because if I give up hope, then my illness will win," he says.



PHOTOS BY INTAN NUR ELLIANA ZAKARIA AND SYAZWAN AFIFI ISMAIL

## **MASMIR ZAINAL ABIDIN, 24 (CANCER PATIENT)**

To be told that you have cancer at a young age will put you on a roller coaster of emotions.

"It was horrible and nerve-wrecking. I was shocked and angry. I lead a healthy life. I didn't smoke. I loved sports and I ran. I watched what I ate so I could not understand why I had cancer," says Masmir.

"To make matters worse, I had testicular cancer. This was even more depressing as I thought that I would never have children. But the doctor assured me that it was at the initial stage and I could have a family," he adds.

In April, Masmir was diagnosed with seminoma, a malignant germ cell tumour. Germ cells become sperm or eggs in the developing embryo. In rare cases during development of the embryo, these cells travel to other areas of the body.

In Masmir's case, the germ cell was stuck on the right side of his vena cava — a large vein in which blood returns to the heart from the head, neck and upper limbs. For the last two years, the germ cell had grown into the size of a man's palm, without Masmir realising it. It was discovered by chance when he went for a check-up because his face swelled after he played badminton.

"I had blood and urine tests. While waiting for the results, the doctor told me to go for a chest X-ray."

It turned out to be a move that saved Masmir's life. The x-ray showed the growth which was pushing into his lungs and heart. A biopsy later confirmed that it was cancerous.

### **IMMEDIATE START**

"I was told it was at stage zero but that I needed to go for chemotherapy immediately. I was totally

unprepared. It was overwhelming," he recalls.

Masmir was put on four cycles of chemotherapy. Each lasted 21 days. After the last cycle, the growth had reduced to about 2.5cm. The doctor recommended an additional two cycles to make sure the growth shrank further.

"The treatment was horrendous. I vomited. I didn't have energy. My hair and my eyebrows fell off. I became fat and had low calcium count. I was in pain. I hated every moment of it," he says.

His attitude changed when he spent time at the daycare centre where he met other cancer patients. Most of them were older than him and were in worse condition.

"I realised that my treatment, although aggressive, was nothing. I have seen patients with one handful of tubes of medicine, while the other hand held a bucket — for vomit. Some underwent radiotherapy which had even worse side effects. I stopped feeling sorry for myself and started to count my blessings," he says.

He was studying animation design at Limkokwing University then and had to defer his studies. He completed six cycles of chemotherapy last month. Since there is still 1.3cm of the growth, the doctor has advised him to go for an operation and more rounds of chemotherapy. He has decided not to do it.

"I know that I won't survive more chemotherapy. I know that my body cannot handle it anymore. When I did the first cycle, I could feel my heart stopping. After the sixth cycle, I had several fainting spells and my hands and legs were numb. I don't want to go through that again," he says. "The tumour may grow again. But I will take my chances. I am trying alternative medicine now. I take herbal products and energy drinks."

*"The tumour may grow again. But I will take my chances."*

*Masmir Zainal Abidin*