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Struggles of an HIV-positive mother

Norlela says she was more worried about her four children.
— Picture by Razak Ghazali



KUALA LUMPUR — A mother of four was forced to choose between HIV medication and her children.

Norlela Mokhtar, 50, was diagnosed 14 years ago as being HIV positive and three years later, she was in dire need of medication but medical care for HIV patients was not free.

"It cost about RM1,000 a month and I did not have that kind of money because I was working as a clerk at that time," she said.

"I had to choose between myself and my children.

"I had to choose between paying for my medication or to feed my children."

She avoided doctor's visits and check-ups to avoid being asked to take the medication.

"In 2005, I had tuberculosis and I had no choice when I was admitted," she said.

"Prof Dr Adeeba Kamarulzaman (Malaysian AIDS Council exco member) started me on the anti-retroviral treatment, even though it was not free at

that time."

It was then that she regained her health, along with her weight.

"I was a skeleton of about 50kg as I lost so much weight. I was only 30kg at that time," she said.

Norlela was advised by a friend of hers to get tested because her former husband was an intravenous drug user (IDU).

She believes she contracted the disease from him.

"In that year of being diagnosed, I had no support," she said

"At that time, whatever they said did not have any impact on me because I was thinking about my four children, who were between two and 10 years old."

She went on with life without acknowledging the disease but remained a strong front for her children.

"I made sure I was strong in front of them," she said.

Norlela recalled the discrimination she faced, from both family and friends, but she has no regrets.

"My youngest child was taken away from me by my stepmother for fear I would infect my children," she said.

"In the office, they didn't let me go to the canteen or use the items in the pantry.

"However, I am not angry with them because they didn't know how a person was infected."

An advocate for those like her, Norlela formed Persatuan Wahidayah Malaysia (Pewahim) and the Rumah Wahidayah, a shelter for women and children living with HIV/AIDS.

She believes building a "zero discrimination" nation towards those infected with HIV/AIDS was the first step towards building a HIV/AIDS free nation.

"People are not able to get married, get a proper education or even get loans just because they are infected by HIV or AIDS. This needs to stop," she said.

"People should also be educated, instead of taking HIV tests only when required."