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# Battling disease and stigma

What sets HIV/AIDS apart from other diseases is the glaring fact that there are pockets of people who cannot look past what causes it to be transmitted.

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**I**NTERNATIONAL AIDS Memorial Day is commemorated worldwide today. Since 1983, it has been coordinated by the Global Network of People Living with HIV and remains one of the world's oldest and largest grassroots mobilisation campaigns for HIV awareness.

This year's theme is "Promoting Health and Dignity Together".

What sets HIV/AIDS apart from other diseases is the glaring fact that there are pockets of people who cannot look past what causes it to be transmitted, especially when it concerns unprotected sex and "dirty needles".

This perception gives rise to the ugly spectre of stigma and discrimination that further marginalises those in the high-risk groups including drug users and sex workers. Sympathy is more forthcoming if it involves women and children, who might attract remarks such as "Oh, poor things, it is not their fault."

In Malaysia, the battle against HIV/AIDS continues with both government and non-governmental organisations striving to fur-

## Entrenched in stigma and discrimination

ther reduce the rate of infection.

According to Health Ministry statistics, the number of new infections detected in 2011 was 3,479, which shows a decline compared with the 3,652 cases recorded in 2010. The figures have been declining since the peak of 6,978 in 2002.

The reduction in the rate of infection is commendable and there will come a time when, as Malaysian AIDS Foundation (MAF)

chairman Prof Dr Adeeba Kamarulzaman says, there is a need to "normalise" HIV/AIDS as it is treatable.

"Putting aside how someone gets HIV/AIDS, it is no different from any other disease. You can lead a normal life. But in Malaysia, we are still entrenched in stigma and discrimination," she says.

To normalise the disease, she says it is important to get several things done, such as getting more people tested, to the point where there is "nothing special about it".

The ever-energetic Dr Christopher Lee is quick to emphasise that the younger generation has a better understanding of HIV/AIDS, and this has led to a crop of healthcare professionals who have no aversion to treating patients.

This attitude is making patients more comfortable and secure when seeking treatment, leaving Dr Lee optimistic about the future.

"The onus is on me to make you feel welcomed," says the infectious diseases senior consultant and Hospital Sungai Buloh Medical Department head. "Once the staff accepts them, there is no longer any issue or problem. It is the culture and philosophy of the department."

There is still the issue of some providers being reluctant to treat people living with HIV/AIDS, he admits, but this number has lessened.

"The new generation is more 'enlightened'. Maybe it's because they have lived longer with the (knowledge of the) disease. Besides, they are taught about it in medical school. Those trained in infectious diseases are different because they come in with the ingrained philosophy to not judge."

Dr Lee, who was instrumental in setting up Ward 54 at the hospital for people with HIV, adds that there are also more doctors and nurses who are opting to care for the patients.

"I could hardly find anyone who wanted to work in Ward 54 (when it was first set up). Now, we have nurses getting their post-basic qualification in HIV counselling," he says. "It is a significant step forward."

Other steps towards the right direction include HIV screening for pregnant women and access to free first-line antiretrovirals medication from the Government, adds Dr Lee, who is also Kuala Lumpur AIDS Support Service Society president.

### Staying alive

While the outlook in reducing the rate of infection is good, there are challenges faced by those who are currently running programmes for people living with HIV.

For the Faith Helping Centre, raising funds to keep it running continues to be an upward climb for Michael Chow.

"It is not easy because the public tend to be more giving to others like orphans or old

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folks," says Chow who is living with HIV.

Now into his 18th year of running the shelter, Chow says it takes about RM15,000 to RM20,000 monthly to run. This includes rental for two houses, wages for two caregivers and the utility bills. The shelter currently has 16 residents.

The allocation he normally receives from the Malaysian AIDS Council (MAC), which it obtains from the Health Ministry, has been reduced this year, and he is now scrambling to find the cash to keep the shelter running.

"We are struggling but there are some people who give what they can to help us because they know we are doing good work," he says.

Residents who can afford to pay are charged RM400 monthly and he sometimes obtains funding from his church and friends.

Chow thinks nothing of using his own cash just to keep the shelter afloat and has dipped into his own savings. Those who stay with him and are employed also chip in with what they can spare.

"You can't just chase people out. If we close our doors, where are they going to go? They will be homeless."

For someone who has been helping provide shelter for women and children for about 15 years, Wan Hava Wan Hussin, who is fondly known as Kak/Mak Wan, agrees that it is easier to obtain funds for children as the public tend to be more sympathetic.

Upon retirement as Rumah Solehah supervisor, Kak Wan founded a shelter for boys called Positive Shelter three years ago. She relies on public and corporate donations besides obtaining cash from her EPF savings to pay monthly expenses of up to RM9,000.

PT Foundation chairman Hisham Hussein says it is a two-pronged approach when it comes to funding. There needs to be government commitment and public support.

"For some members of the public, if the cause is 'sexy', then they will bring the money," he says. "Some time ago, a donor bluntly told me that HIV/AIDS was passe and it was now cancer."

The Health Ministry's financial assistance to NGOs through the MAC has not been "rolled over" from previous years, resulting in financial difficulties for the NGOs, he says.

The foundation, formerly known as Pink Triangle, is a community-based organisation that provides information, education and care services related to HIV/AIDS and sexuality. It works with the five communities that are most affected by HIV/AIDS such as drug users, sex workers, transgenders and men who have sex with men.

Hisham says the foundation, which is now into its 25th year of existence, has to come up with RM30,000 monthly for operational costs.

"It is a struggle because people tend to be judgmental," he says, adding that the public do not mind giving to children or women who were infected by their "naughty" husbands.

He says it is also difficult to obtain funding from companies under their corporate social responsibility programmes due to the communities that Pink Triangle represents.

In terms of fund-raising for the MAF, Dr Adeeba says the Sapura and Kencana Petroleum Red Ribbon GP Ball 2012 raised about RM1mil to benefit their various programmes and activities.

In an interview in conjunction with International AIDS Memorial Day, Health Minister Datuk Seri Liow Tiong Lai admits that maintaining current levels of financial commitment, developing efficient and transparent systems for allocation of financial resources and establishment of a national monitoring and evaluation framework were challenging.

He adds that allocation for HIV/AIDS has been increasing annually with RM61.6mil in 2010, RM67.6mil in 2011, and RM73.5mil this year. Some RM59.59mil had been disbursed to the Malaysian AIDS Council over a nine-year period from 2003, he says.

The amount has exceeded what the Government committed to in a memorandum of understanding signed nine years ago, for the period of 10 years, which was RM40mil, Liow says.

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**Better funding:** AIDS Memorial Day is commemorated worldwide today with the theme 'Promoting Health and Dignity Together'. In Malaysia, allocation for HIV/AIDS has been increasing annually with RM61.6mil in 2010, RM 67.6mil in 2011, and RM73.5mil this year. – AFP