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Kasih, where HIV patients find compassion, support

'The sufferers are referred to us by the hospitals, notably Queen Elizabeth Hospital. There are about 50 sufferers, adults and children, registered with us at the moment. Mostly, we talk to them, counsel them, comfort and advise them. This is a place where they can talk openly and get comfort from the counsellors here and also their fellow sufferers'

Currently we have 12 single mothers that are HIV positive and are accorded financial assistance of RM150 each.'

Monica Thien, Head of Kota Kinabalu AIDS Support Services Association.

By Anna Vivienne

Despair is most felt when someone is told that he or she has contracted HIV or Human immunodeficiency virus. They are not only scared of the suffering they may have to go through but also by the fact that their family may disown them or they will be ostracized by society due to the stigma attached to this condition.

Their anguish may further be amplified by their lack of understanding of the much feared ailment that makes the human immune system fail leading to life-threatening opportunistic infections.

Kasih, or Kota Kinabalu AIDS Support Services Association, which is looking at the disease differently, is undertaking the daunting challenge in providing the much-needed help and support the patients may not otherwise receive elsewhere.

Headed by retired nurse Monica Thien and sited at Taman BPL off Kebajikan Road, Kasih strives to provide HIV patients with understanding and management of the disease as well as other forms of assistance.

"The sufferers are referred to us by the hospitals, notably Queen Elizabeth Hospital. There are about 50 sufferers, adults and children, registered with us at the moment," Thien says.

She says: "Most people would find out that they have contracted the disease when they come to the hospital for treatment of common ailments, such as persistent flu or fever.

"It is only after medical check up that they were found to have HIV and the doctor will of course inform them.

"This is obviously very devastating for patients but they may gain or boost their immune system when they are treated with a combination of drugs called antiretroviral treatment.

"However, this is a life-long treatment. They are not allowed to go off the treatment at all or they may suffer a relapse. The treatment is quite expensive."

Fortunately in Malaysia, the government sponsors the treatment.

According to Thien, the sufferers are treated immediately for the disease but to keep depression from setting in, the patients are referred to Kasih for counseling and the necessary help.

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According to Thien, the disease, being connected with promiscuity and sharing of tainted needles in drug use is deemed shameful although it must be mentioned that some women sufferers contracted it from their husbands.

There are known cases of sufferers getting it through blood transfusions and vertical transmission or babies infected by HIV positive mothers at birth. In this case, expectant mothers who are HIV positive should tell their doctors.

"Usually, the adult sufferers don't want to talk about it. They don't want anybody to know. Some don't even tell their immediate families for fear of ostracism. So we talk to them and tell them that they cannot infect others by merely eating with them, talking with them or other normal social contact. Unless their blood is transferred to another person through an open wound, or they have carnal knowledge with another person, they cannot infect others."

"Telling them all about choices and disease management is not all; we also look into their welfare and assist them where we can. Currently, we have 12 single mothers that are HIV positive and are accorded financial assistance of RM150 each. That goes towards their bus fare and other expenses when they come to the hospital for treatment."

Kasih is far from coping, however, as there are cases where children with HIV are abandoned by their families due to ignorance or poverty.

"I know of three boys, one of whom is infected. The other two boys were taken by relatives but the one with HIV was left behind. Some are taken by relatives but if they do not take medication on time and regularly, it will still not help. So Kasih needs a shelter for these children. We need to have a proper shelter, not only a place where the sufferers can meet and get their bus fare, but a place where we can take care of the children."

To this end Kasih will shift this month (July) to a rented house in Kobusak,

Penampang. The building, however, will only accommodate 15 children.

"Ideally we need RM100, 000 a year to run this centre. We are not getting a government grant at the moment but we do get assistance from Malaysian Health Council (MHC). The fund goes towards our patients and several other things such as milk supplements," she shares, adding that Kasih also receives public donations.

She concedes, however, that they are seldom, if ever, visited by charitable groups during the festive seasons, unlike other establishments and homes. When other similar establishments ring with the joy and thankfulness of being given foodstuffs and cash during that time, Kasih remains quiet.

"Because of the stigma attach to HIV, these charitable organisations are not too eager to be with us. Perhaps they are afraid of being infected by the disease," she says. She hopes that the public perception of HIV will change in future.

Kasih holds awareness campaigns periodically and have carried out various campaigns at the Gaya Street Fair.

Meanwhile, Sabah recorded 126 people aged from two to 50 years old suffering from HIV last year. In Malaysia from the year 1986 to 2009 there were 87,710 HIV cases and 15, 317 AIDS deaths.



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A Kasih sign at the centre's grounds.