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Saving lives by changing attitudes

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THERE is a disease which is taking the lives of 5,900 people per day across the globe. In Sarawak the number of infections has quadrupled in the last seven years. It can affect old and young.

Yet as soon as the disease is named people would switch off. They mistakenly think it is nothing to do with them.

Even worse, instead of reaching out to help the people coming to terms with their diagnosis they shun them. The illness is AIDS, which in its early stages is HIV.

Today, May 17th, is the day people across the world are asked to remember those whose lives have been cut short by this epidemic.

It is also the day we should learn from their experiences. By listening we can learn how to improve our care for those who live with the condition and prevent our loved ones from becoming affected.

Sarawakian's experiences

Nine years ago a woman gave birth to her third child. A time for joy but short lived. The mother had been infected with AIDS and died shortly after. Sadly the baby and one of her other children were also affected. With treatment the father was able to see his children grow but then he too passed away.

Today the grandmother is struggling to cope emotionally and financially to raise her lively grandchildren. They do not yet show any signs of their illness.

With advances in treatment their life expectancy is expanding. Like any grandmother she wants them to have a good life but she fears losing them; fears she will go before them and fears others will avoid them due to ignorance.

The children have lost so much already — they need to stay with their family, their friends and their community. Is the understanding and care there

to support this family?

In another family, in a different Sarawak community, two children were similarly orphaned — first Mum then Dad. This is not an uncommon sequence regardless of who was infected first as, for a variety of reasons, women have greater vulnerability.

The children's mother was shunned by her in-laws and separated from her offspring. No dying at peace with her loved ones around her for this mother.

Her one comfort was the knowledge that her children were free of the disease. She was not to know that after she died the children were rejected by all their relatives and left to be raised by strangers.

Why the rejection?

Fear, ignorance, and prejudicial attitudes are the main reasons. They stop people thinking rationally and responding empathetically to the person with the condition and those supporting them.

HIV/AIDS is no longer a new illness but people still have not thought it through. They still have an unwarranted panic reaction.

This was demonstrated when a person who was working in the north of the state came to Kuching to give his personal testimony of living with the condition to help promote understanding.

He was trying to encourage more prevention and support to those already infected. Those who listened were very moved and applauded his courage but somehow his employers heard about his health status. When he returned to work, he was sacked.

This panic reaction was devastating for the man and also damages the state's attempts to tackle the epidemic.

When society is so callous people are frightened to find out whether they are affected or not. Delayed testing means delayed treatment, less prevention and more lives lost.

People need to learn that there is nothing to fear from

working and socialising with people with the disease. The virus cannot survive outside of the body. It can only be spread by direct body fluid contact from one person to another. It is safe to eat with, hug and kiss someone with AIDS. It is essential that ignorance and complacency are overcome.

Why complacency?

Although it is well known that HIV/AIDS can be transmitted through sexual intercourse — heterosexual transmission being the main mode recorded in Sarawak — people seem to think it will only affect others and not them.

This is only so if neither partner has had sex with anyone else for more than ten years as it can take that long for the person to feel unwell. Just think what you see going on around you and you will realise why complacency needs to be tackled

Sarawak AIDS Concern (SAC), an active NGO trying to reach out across the state, worries about the number of people who do not take any precaution to prevent the spread of the disease through sexual activity. In their view, if people find it too difficult to contain their desire — or don't want to — then they have to realise they are putting themselves at risk of catching the disease unless they wear protection.

Faithful partners also need to realise they can be at risk if their other half has not been — or had a relationship prior to meeting them. They note people are complacent as they do not think they, or their partner or their teenage children are at risk — for many this is a fallacy.

The need for urgency

Action now can save lives. Don't wait until it is your family who has a loved one affected. Already we have families in every division who have members with the disease. Some live in rural areas, others in town, others have left the state to hide.

They need our support now so they can live a life of quality within their own communities. By changing our attitude from

stigmatising people to helping them we are building a more caring society — one which will be more accepting of any of our own family members who may one day be affected.

Such attitudinal change will also help the prevention of the disease.

With over a 50 per cent increase in HIV cases in the first three months of this year compared to last, waiting is not an option.

Together we are the solution

This is the international theme for this year's Memorial Day. To bring hope to those affected and to reduce the spread of the disease we need to work together.

Education is needed so people do not panic and exclude people. Education is also needed so people know how to protect themselves and where to seek help. Everyone has their part to play — employers, neighbours, relatives, community leaders, a range of government departments and NGOs.

This year, Malaysia is asking the religious communities to take the lead and reach out with kindness to those who are living with the disease. All faiths call on their followers to help those who are ill, yet many still treat people with the disease like our forefathers treated lepers. It was wrong then, it is wrong now.

If you want to be part of the solution SAC would be happy to hear from you. Learn more about their work from their website www.sarawakaidconcern.org. People who want to participate in their memorial event on June 13th; arrange talks; have queries about the disease or would like to know where to go for confidential testing, are all welcome to contact 082-233173.

(Gill Raja is chair of the Sarawak AIDS Network and a lecturer in social work at Unimas. Details of local situations have been abridged to protect people's identities.)