

'I'm not meant to die'

When Sheila* found out she had caught HIV from her husband, everything she had loved about him felt like a lie. A greater lie lay ahead – her children cannot know she's about to leave them. She shares her heartbreak with CRISPINA ROBERT.

“M

y life changed in 1999, at the end of the year. While people were celebrating their hopes for the new millennium, I spent days and nights staring at the walls of my living room, not able to eat or sleep.

Weeks before, my husband had applied to become a Singapore permanent resident. Those were hopeful days. He had been a “foreigner” for so long that our three children thought daddy was a sailor: He had to leave Singapore every few months to renew his permit. When he made up his mind to plant both feet on my half of the ground, I felt a quiet relief – he was finally ours.

As part of the application process, he had to get a medical check-up, which I was certain he would pass, because he was robust and had a healthy appetite for life, even in his 50s.

We had married when I was 20; he was much older, and my parents disapproved. How well do you know him, they had asked me. Has he told you enough about his past, where he grew up, and what he's been through? But he was my first boyfriend, I was in love, and I didn't know better. Maybe I didn't want to know better. And so we went ahead with our modest wedding and as a consequence, cut ourselves off from my family to avoid further tension.

We had three children – two beautiful girls and a boy – in quick succession. He worked as a food supplier and travelled a great deal – he could disappear a whole year at a time, mostly to the Middle East – while I stayed home to mind the kids. When I caught him in a good mood, I would hint that the children would like to see more of him, maybe even have him take them to school sometimes, or play games with them.

The day he got his medical results, he called and told me to drop the children off at my neighbour's house before meeting him. I couldn't imagine why. Did he have a pleasant surprise in store for me? A dinner date because he was halfway through the door? Or maybe it was bad news – he always suspected he had high blood pressure from all his heavy drinking and eating, which could mean a lifetime of medication. But when I saw him at the coffeeshop near our house, I was thrown off completely. He started crying.

I remember just staring at him, then disparate thoughts started rushing in. I knew what HIV was; it's what you see on TV, in educational ads and sterile documentaries. People waste away and die lonely, scorned by everyone except social workers. He kept rambling, saying he was sorry, over and over again. My mind jammed up, unable to process the lurid truth mashed with tears that he was shoving at my face.

My husband could die... he could die... And in an instant, it struck me: Could I have it too? And worse, could our children? The fear started to spread and I couldn't stand myself up, as my →

I knew what HIV was; it's what you see on TV, in educational ads and sterile documentaries.

mind tore between my own death, his death, and losing my children. The last thought drove the arrows of this fast-evolving tragedy straight into the heart, and he had to help me while I cried all the way back home. I rushed to see my children, to grab them in my arms. The oldest was only eight and my youngest not even two years old. I tried not to frighten them with my tears and remember stumbling into the toilet to muffle my wails.

It was strange how, when the doctor pronounced that my blood tested positive for the disease, I did not cry. Overnight, my blood had chilled and I must have prepared myself for the worst and saved my fears for my children. After I hauled them to the same doctor for testing

the next day, waiting for their results was harder than the night before. How could I bear to see my babies suffer? The eldest wants to make a snowman and her father promised to take us on a winter holiday soon. The middle one is about to make new friends at daycare. My youngest seems bright enough for great things someday... what will become of their lives now?

At one point, I decided that if they tested positive too, I would kill us all and end our misery before they begin to suffer. My children were innocent. How can I explain to them that it was their own father that had brought them such pain?

I was so angry with him, our relationship ended that night he spelt out our fate. Suddenly, against our natural curiosities, I didn't want to know how he contracted HIV. I wanted him to take complete blame for the fate that had befallen our happy family and any attempt on his part to mitigate could dilute my anger. It helped that he had to leave the country immediately, according to the law.

My husband would return to Singapore several times a year after that, to see us. He died two years ago, five years after his diagnosis.

People think that those who contract HIV did something to deserve it, and that only loose women get it. Not in my case.

To my relief, none of my children tested positive for HIV. But our lives changed nonetheless. They have worked it out that mummy isn't well: I am constantly in and out of the hospital, and have been looking and feeling progressively tired; walking to the bus-stop just 30m away makes me feel faint.

And they often went hungry. My part-time salary wasn't enough for me to put three meals on the table – there were days when I wouldn't wake the kids up for school so they wouldn't ask for breakfast or pocket money for lunch. Thankfully, when my friends learnt of my troubles, they chipped in until I found a stable job in sales and placed the kids in subsidised daycare.

I can't describe how hard the past eight years have been. My body aches and my head throbs constantly. My liver is failing because of the disease, so I catch infections really easily. Every other day, I'm having either a cough, a cold or high fever, and can hardly eat. When I was on medication, I felt better on the whole, but I had to stop because it cost me \$900 a month.

Recently, I collapsed while at work, and was rushed to the hospital bleeding from the mouth and nose. Doctors told my sister that she should prepare for my funeral, but I woke up one week later. They have given me two years to live.

I have asked my sister and her husband to take the kids in when I die – they are the only relatives who know my situation. To my kids, I tell them I have an "illness", because I can't bring myself to tell them I have HIV. How →



Red flags

Last year, there were...

...**3,060** HIV-infected Singaporeans, of which 357 were new cases.

...**1 in 350** Singaporean hospital patients was found to be HIV-positive in a random test & unaware he or she has contracted the disease.

! In Singapore, the majority of men infected with HIV or Aids get it from engaging in casual, unprotected sex; the majority of women get it from their husbands or boyfriends.

does a mother tell her children she is dying? It will rob them of all their innocence and happiness. And dying of a disease like this? They won't be able to understand that it is not my fault. They may think I am dying from something ignominious, and have wronged them somehow.

But we have talked about death. I asked them which aunt they would stay with if I die. They told me not to talk nonsense. When I press the issue, they say they won't stay with anyone, they'd rather die with me. It comforts me yet breaks my heart, because none of us was meant to die yet. Not this way.

My second daughter is especially close to me. She sleeps with me and when I am sick, she wakes up constantly to put her finger under my nose just to check. Thinking about them worries me all the time. The social worker says I have to prepare them for my death but I just cannot bring myself to talk to them about it.

So I refuse to think about tomorrow or next week. I think only about today and what we can have

for dinner or to make sure they study for their exams – only the small things, because I know my body is failing, I can feel it. But I try not to think about it; when I do, I get very frightened and I know it will affect my kids.

I have asked God for a little bit more time – just five years more – so the

youngest one will be older and able to take care of herself... without her mummy...

People think that those who contract HIV did something to deserve it, and that only loose women get it. Not in my case. My husband was the only man in my life and I've seen so many others just like me. When you are married, you have sex with your husband because you trust him. But I really should have been smarter. He travelled so much, I suspected he was engaging in risky behaviour and sleeping with other women, but I simply let it pass.

This is something I would never wish on any mother. Every day, when I wake up, I thank God for giving me one more day to see the faces of my children because I don't know if it will be the last time I can do that." **HW**

** Name changed to protect her identity*

NOTE: A few days after this interview was conducted, Sheila was fired from her job for looking too sick to do her job well. Her employer doesn't know that she has HIV. She is now searching for another job.

Risky behaviour

+ **If you suspect** that your spouse or partner may not be faithful, or you have had unprotected sex, you can get an anonymous test done at the DSC Clinic in Kelantan Lane. All government hospitals, clinics and polyclinics also provide testing services. Call 1800-252-1324 during office hours to speak to someone.

+ **The Government is getting serious** about infected persons who engage in risky behaviour. Aside from routine pre-natal HIV screening for all pregnant women, a proposed amendment to the Infectious Diseases Act is now under public consultation. Under this amendment, anyone found guilty of having unprotected sex, even if they did not know but had "reason to believe" they have been exposed to the virus, can be jailed up to 10 years and/or fined as much as \$50,000.

+ **Getting fired from their jobs** because of their condition, not being allowed to have their children enrolled in school, disowned by their families, forced to use different sets of utensils and being shunned by society... These are just some of the humiliating scenarios HIV/Aids patients face every day.

"Most people do not want to be associated with them because of the moral implications of the disease. But we shouldn't discriminate against them because they're already bearing the brunt of their doing," says Amutha Meyyappan, a frequent volunteer at the Communicable Disease Centre's Patient Care Centre, which provides services like rehabilitation schemes and employment for HIV/Aids patients.

Currently, only 75 patients are under PCC's medical subsidy scheme for their medication which costs US\$1,500 (\$2,200). Another 125 are on the food ration scheme which ensures a reasonable standard of living for needy patients.

To know how you can help more patients, call PCC at 6357-7900.

ADDITIONAL REPORTING GLADYS CHUNG

