

# *Need to maintain trust with people living with HIV*

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For The Straits Times

On Jan 28, news broke that the personal details of 14,200 individuals had been stolen from Singapore's HIV Registry, and subsequently leaked online.

As doctors who care for people living with HIV and their loved ones, and members of the Society of Infectious Disease (Singapore), we were dismayed as our patients, whose confidential information was compromised, started to call in to our clinics in shock, disbelief and distress.

In the days following, much has happened. There has been an increase of activity among civic society and individuals alike, almost universally expressing support and solidarity for those now living in fear that their intimate medical and personal details may be public knowledge.

There is debate ongoing on a range of issues related to the

matter, such as the legal frameworks surrounding HIV and those affected by it, the role of mandatory HIV notification, and the security of medical informatics systems in our rapidly changing healthcare landscape.

Our priority as healthcare professionals has been working hard to ensure that those under our care are safe and supported during these extraordinary times. Doctors, as well as nurses, medical social workers and other front-line staff, have been on the ground, addressing the many questions that patients have, as well as providing counselling and reassurance to those particularly distressed. This is, of course, an extension of the work we already do, and the calling we already heed: providing holistic, comprehensive and compassionate care for a group of people on the margins of society.

As a community of practitioners providing care for people living with HIV (PLHIV), we want to assure Singaporeans, especially patients and family members, that we will work hard to make sure that PLHIV in Singapore receive the

highest standard of care that is multi-disciplinary and holistic, with the aim of ensuring their physical and psychological health.

This care is being provided by a number of public healthcare institutions, and comprises not merely specialist HIV clinical care, but also primary care, psychosocial support services and allied health services.

The goals of HIV care go beyond the prolonging of life, to include the assurance of quality of life. Prevention of HIV infection is also of vital importance, and we pursue this through traditional and innovative prevention strategies.

Close cooperation between care providers, community-based organisations with a focus on HIV, policymakers and public institutions, academics and researchers, and most importantly, affected populations, is needed to ensure the continued success of HIV care programmes in Singapore.

PLHIV also need society to fight HIV-related stigma and discrimination. The stigma of HIV/AIDS and the discrimination faced by those who live with it

remain a pressing problem today. Most patients under our care still keep their diagnosis a secret from friends and family; many fear rejection at work, school or home.

One of the core values guiding the provision of HIV care is that PLHIV should be treated with dignity and respect. We can reduce HIV-related stigma and discrimination in Singapore by raising awareness of key messages.

First, that PLHIV can live healthy, happy and productive lives of normal life expectancy if they are started on, and remain on, effective anti-retroviral therapy. HIV is no longer a life-limiting diagnosis, and with access to treatment, people living with HIV are no different from people living with other chronic diseases like diabetes and hypertension. However, this can be achieved only if people at risk of infection come forth for testing, and if tested positive, come forth for treatment. We believe this is best achieved through increasing knowledge and awareness of HIV/AIDS, and reducing the stigma associated with the disease.

Second, that HIV infection

cannot be transmitted through casual contact. There is now incontrovertible evidence to show that HIV-infected people who are on effective treatment have undetectable levels of virus in their blood, making it impossible for them to transmit the infection to others – a paradigm now known as Undetectable = Untransmittable, or U=U.

Hence, we strongly feel that workplaces, schools and other public institutions should take the lead in treating people living with HIV fairly and equally, and protect their rights to employment, education, access to care, and service to society.

Third, and perhaps most importantly, is the fact that HIV infection does not discriminate, and can affect people of any sex, age, ethnicity or sexual orientation. Our patients come from the whole spectrum of society – young and old, man and woman, of every sexual orientation and socioeconomic class. Just as we should not treat people differently based on any of these characteristics, neither should HIV status subject any

person to discriminatory treatment.

We are aware that much needs to be done in the light of the damage of recent days, and to maintain the trust of our key constituents – namely, people living with HIV to whom we provide care. This will not happen overnight, but is a task the importance of which cannot be overstated.

By recommitting to the objectives set out above, we hope to build a strong and trusting relationship with people living with HIV. Recent events have shown how much fear and taboo still exist around HIV. It is our belief that by working together, we can overcome the challenges ahead, and make life better for all, regardless of HIV status.

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