4 September: The tip of the iceberg

September 4, 2015 By David Pieper

I am on holiday in Bali, staying with an old friend who lives here now. In the past 25 years we have barely spent more than one hour in each other's company, as we have both lived and worked all over the world, but happily we are getting on like it was just yesterday we were piling into my car, along with six others, to gate-crash a party.

I realise being in Bali probably sounds very exotic to American and European audiences. But for Australians it is the equivalent of going to Hawaii or Majorca. There are so many Australians here, the locals use Australian slang to tempt you into their bars or to purchase their trinkets. But everyone is genuinely friendly and chilled.

While the life of my friend has taken a very different course from mine, we have both ended up HIV positive, while I have the added "bonus" of hepatitis C. We talk about our lives and philosophies and our various experiences of diagnosis and treatment. We also talk about disclosure and he is inspired to be an activist like me. While treatment is available for HIV in Indonesia, supply of drugs is uncertain. There is no community-based information and stigma and discrimination are rife. A local expat newspaper features an article on HIV denialism and the author is unconvinced that HIV treatments themselves are not the cause of AIDS. I am angry that he provides a platform for these views and write to him to explain the effect this will have on poorly informed people. In doing so, I discover that there are 25 million people living with viral hepatitis in Indonesia. 10% of the population has hepatitis B alone, the third highest prevalence in the world. 80% of them are undiagnosed. This is a tragedy. It puts my treatment experience into context and I realise that I am the merest tip of the iceberg.

Meanwhile on the other side of the world, my partner is attending the first ever Global Hepatitis Summit in Glasgow. I am following the twitter feed and I am pleased to see this unprecedented global event to eliminate viral hepatitis is patient-led. Health Ministers from nine countries (not including Australia) are present. With 1.4 million preventable deaths from viral hepatitis, we need governments of all jurisdictions to develop and implement comprehensive, funded, national hepatitis programs in partnership with all stakeholders. We need realistic yet aspirational global targets for prevention, diagnosis, care and treatment (paraphrased from the Glasgow declaration on viral hepatitis). There is plenty for me to do, so that my hepatitis experience can have some impact on this iceberg.

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