

The Chair

Victorian Legislative Council Legal and Social Issues Legislation Committee
Parliament House, Melbourne

I write as an academic and sociologist who has worked in HIV/AIDS social research professionally since 1986, both in Australia and internationally. I am the Deputy Director of the Australian Research Centre in Sex, Health and Society at La Trobe University, one of four national HIV/AIDS research centres in Australia. I am also an Ambassador for Dying with Dignity, Victoria.

I wish to bring to the attention of the committee issues related to the current inquiry, in particular those lessons we have learned from the HIV pandemic over its now 33 years of existence. The first AIDS death occurred in Australia in 1982. Over 28,000 Australians have been infected with HIV since then, and over 1,200 new infections still occur each year.

Many now think that HIV/AIDS is over, particularly in Australia, with successful treatments now widely available for people living with HIV, at least in the developed world, and death no longer an inevitable consequence of an HIV infection. That is partly true.

My first friend and colleague to die of AIDS did so in 1984; the most recent death among my circle of friends and colleagues occurred in June this year—yes, 2015. People are still dying from AIDS in Australia despite available treatments. For some, the treatments do not work; for others, they do not work well enough, and years of partially effective treatments have left their bodies seriously damaged and prone to other debilitating conditions.

It is true that the majority of Australian people living with HIV are now living well compared with five, ten or even twenty years ago, but it has been a long attenuated struggle to reach this stage. My Centre is now involved in a new project looking at potential social aspects and consequences of current biomedical research on any HIV 'cure', the possibility of which is still many years away, and we still have no efficacious vaccine after 25 years of research. For people living with HIV and those newly infected, HIV/AIDS is still a life-changing and life-long struggle.

I raise these issues to remind the committee of those 33 years of struggle, during which over 11,000 Australians died, many long before any form of even partial treatment was available. Many suffered greatly as a result. An unknown number killed themselves, including colleagues and friends of mine, and they had to do so in circumstances that go to the heart of the issues concerning your enquiry into end of life choices.

For some, the struggle of living with AIDS, the end stage of an HIV infection, was too much, too devastating, too painful for them and their loved ones. Their deaths had to occur in secret, often alone, unassisted, and difficult to achieve. While many found support among friends and family during their illness, for others during that long struggle Australia was not always supportive of people living with HIV and the communities most affected, particular gay men (who were then and still are today the subject of discriminatory laws in Australia). The stigma of HIV infection was a terrible burden then. It still is, as the current campaign of the Victorian Positive Living organisation 'ENUF' attests in its call for an end to stigma related to HIV/AIDS.

Throughout the epidemic in Australia, despite an excellent public health policy history, people living with HIV and their affected communities have constantly been forced to defend their rights, fight unnecessary criminalisation (recently changed in Victoria, to its credit) and discrimination, and endure prejudice. Times and things have largely changed for the better over that 33 years, but this is the context in which the communities fighting HIV/AIDS have lived and in which those living with HIV or with AIDS itself chose to die at their own hands.

There will be many submissions to your committee focusing on particular illnesses, conditions and circumstances. There are a number of specific lessons from our experience of the HIV epidemic in Australia that pertain to your committee's deliberations.

1. We often hear exhortations that 'a cure or better treatment is just around the corner so do not contemplate your own death'. HIV/AIDS has humbled our twentieth century optimism in medical scientific advances. It was 14 years until the beginning of treatments that were only partially effective (but often debilitating); 33 years later we still do not have a 100% effective treatment, let alone the 'cure'. There are many illnesses and conditions where the cure is not just around the corner, and for which medical science will remain baffled for long periods of time. A death with dignity should be an option for those suffering the insufferable and interminable.
2. There will be new conditions akin to HIV/AIDS that will also have lengthy periods of failure to find treatments and cures, leaving those inflicted with them to suffer for long periods. New viruses are being discovered all the time, e.g. SARS, MERS, bird flu, and others are jumping the species barrier, e.g. the Hendra virus, in our increasingly interconnected and interdependent world. Many of these may lead to quick, painful deaths as we have seen with Ebola, first discovered in 1976 and only almost 40 years later do we see a promising vaccine. Others like HIV/AIDS may have long periods of suffering with no treatment or cure in sight for generations. Policies that allow people inflicted with these untreatable diseases and conditions to choose to die with dignity are needed now in preparation of the next virus, the next epidemic, the next environmentally caused havoc, e.g. Chernobyl, Fukushima.
3. Even with new treatment and scientific breakthroughs, many living with serious conditions carry a high burden of suffering. It is wonderful to see people living with HIV living longer, but not so for those experiencing life-debilitating conditions caused by the infection itself and the body's response to it and/or by treatment side-effects. There are serious Quality of Life issues here. These compounding circumstances render the existence of treatments inadequate as argument against choosing to die with dignity when the quality of one's life is greatly outweighed by one's suffering.

These are some of the lessons we have learned from the history of 33 years fighting HIV/AIDS, and as the much-misquoted Spanish philosopher George Santayana actually said in 1906: 'Those who cannot remember the past are condemned to repeat it'.

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