22 May 2013

The Hon. Cate Faehrmann, MLC Parliament House Macquarie Street Sydney NSW 2000



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Dear Ms Faehrmann

Positive Life NSW¹ and ACON² are writing in support of the *Rights of the Terminally Ill Bill 2013*.

We would like to commend the NSW Parliament for considering the Bill to provide a person who has a terminal illness and who is experiencing unacceptable pain, suffering and distress to request assistance from a medical practitioner to end their life. We believe that the Bill provides strict and acceptable conditions in relation to the operation and monitoring process of the assisted dying process.

We note also that this right is accorded to people in a number of overseas jurisdictions, including the Netherlands, Switzerland and the US states of Washington, Oregon, Montana and - most recently - Vermont.

The course of HIV infection has changed significantly since the introduction of highly effective antiretroviral therapy in 1996. This has resulted in a decline in the annual number of acquired immunodeficiency syndrome (AIDS) related deaths in NSW. HIV infection is increasingly now regarded as a chronic manageable disease, however a minority of people with HIV will experience extreme pain, suffering and distress before they die from complications associated with AIDS and from other health conditions such as cancer, renal and hepatic disease.

The right to live with dignity has been a central tenet of the way that people with HIV/AIDS have positioned themselves as they fought for the right to engage with health professionals and to self-determine the way they live their lives. The logical corollary of this approach to life is that in the case where an individual believes their pain and loss of dignity is too great to bear, that they have the right to seek some control over the time and means of their death.

¹ Positive Life NSW is the peak not-for-profit community organisation in NSW representing the voice of people with HIV. The organisation works to promote a positive image of people living with HIV by eliminating prejudice, isolation, stigma and discrimination. Positive Life NSW provides health related information and targeted referrals and advocates for changing systems and practices that negatively impact on the health and human rights of people with HIV in NSW.

² ACON (the AIDS Council of NSW) was formed in 1985 as part of the community response to the impact of the HIV/AIDS epidemic in Australia. Today, ACON is Australia's largest community-based gay, lesbian, bisexual and transgender (GLBT) health and HIV/AIDS organisation. ACON works to improve the health and wellbeing of the GLBT community and people with HIV, and reduce HIV transmission.

We know that some people with HIV/AIDS have sought assistance to end their lives at a time of their choice despite the fact that doing so is illegal. Research undertaken by Professor Roger Magnusson's (University of Sydney) on HIV positive people reveals cases of 'botched 'suicide attempts and the dreadful impacts these produced on all involved.

Positive Life NSW and ACON believe that when no other options are acceptable to a person to relieve their pain and suffering, that their rational requests to a medical practitioner to end their pain and distress should be respected and granted.

Yours faithfully

Sonny Williams

Chief Executive Officer, Positive Life NSW

Nicolas Parkhill

Chief Executive Officer, ACON