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HIV and death

By Andy Seale

Today people living with HIV can expect to live as long as others thanks to treatment, nevertheless acquiring HIV can change the way you think about death – and life.

Many people who acquired HIV in the 1980s and 1990s, before effective treatment, did die young. Millions of people. Some, like me, were fortunate and are still around today. Regrettably there are still over 500,000 annual deaths due to AIDS, as roughly a quarter of people who live with HIV do not have treatment or adequate viral suppression.

The stigma and discrimination around HIV/AIDS, partly linked to fear of death, prevents many people from living openly about their status. Some people may choose not to disclose to their closest family members and turn to others for support around end of life planning, for example. Others may have been rejected by their families and communities. The same families and communities who would ordinarily manage the traditions around end of life and death.

HIV brings challenges but also opportunities. I have been fortunate to work with people living with HIV from all walks of life. Many live life in full colour, with joy, humour and humility. I suspect that for many HIV has brought with it perspective and a clear sense of mortality which means each new day is welcomed and enjoyed as a gift. HIV can also offer people an opportunity to challenge and explore the social and religious norms around both living and dying. For some this offers an important and powerful opportunity to reevaluate life and focus on the actions, things, and people that matter most.

For many HIV activists and community leaders at the end of their lives their chosen families come together to celebrate. Typically those gathered do not wish that the deceased rest in peace, instead they are encouraged to rest in power.

HIV can be empowering and life affirming for many who come into contact with it – whether as people who acquire HIV or for people who get to know others living with HIV.

If you are fortunate to have mourners wishing that you rest in power, regardless of your HIV status, you can be sure that you have fully lived and made a difference.

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Date: 2025-07-01

Translation disclaimer: Content originally written in English.