

# British AIDS charity marks 30 years of fear and hope

November 29 2012, by Alice Ritchie

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When Terry Higgins first collapsed, struggling for breath, at London's Heaven nightclub in 1982, he brushed it off. Only a few weeks later he was dead, one of Britain's first victims of AIDS.

Thirty years later, the friends who helped the 37-year-old home that night are still fighting the disease that killed him, as well as the fear and [stigma](#) that continue to haunt the 34 million people living with HIV today.

"I was so goddamned angry," said Martyn Butler, who helped set up a charity in his friend's name with Higgins' boyfriend, Rupert Whitaker.

"Terry was the first. Subsequently I used to make a note in front of my Bible so I wouldn't forget names. I stopped doing it when I got to 50. It was not long after," the 58-year-old told AFP from his home in Newport, south Wales.

This year the Terrence Higgins Trust marks 30 years as one of Europe's leading HIV and AIDS charities with the news that a record 100,000 people are now living with HIV in Britain.

[Health officials](#) view this figure both as a success—because fewer people are dying—and a warning that far more needs to be done to stem infection rates, particularly as almost a quarter of those with HIV do not know they have it.

The Terrence Higgins Trust has been at the forefront of the battle, offering support through its pioneering Buddy schemes in the 1980s and today's back-to-work programmes, as well as providing sexual health services across the country.

It is also a powerful voice for people with HIV, counting singer Elton John, Princes William and Harry and Prime Minister David Cameron among its supporters, amid ongoing public fear about an illness that cannot be cured.

Someone diagnosed with HIV in Britain currently has a good chance at living a normal life provided they are diagnosed early and take their drugs.

"It's gone from being invariably fatal to being a long-term managed condition in just 30 years, and that's extraordinary," said Nick Partridge, the chief executive of the Terrence Higgins Trust.

"But because it continues to be transmissible, levels of stigma and discrimination stick to HIV in a way that all of us hoped we would have shaken off."

This stigma was one of the main reasons Butler and his friends set up the trust in his east London flat in 1982.

They spent countless hours spreading the message of safe sex and providing support to the relentless wave of newly diagnosed men who were facing a death sentence—in the face of often staggering ignorance.

Butler recalled visiting a friend with HIV in hospital, where "they were sliding his food under the door. I had to put on a spacesuit to go into his ward.

"I sat on the end of his bed, took off the spacesuit and there was a scene like out of a science fiction film. I had the nurses and doctors banging on the glass saying, 'put it all back on!'.

"I stuck my fingers up at them and gave him a hug."

Butler admits he had no idea at the time that HIV could not be transmitted through touch, "but I had a gut feeling".

The late Princess Diana played a huge role in combating discrimination against AIDS victims, notably by shaking the hand of an HIV-positive man at the height of the AIDS epidemic in 1987.

Her sons William and Harry have carried on her work and this week wrote to the Terrence Higgins Trust to congratulate it on 30 years of "selfless service" and urge their generation to "pick up the sword and continue the fight".

The global focus on HIV and AIDS is rightly focused on sub-Saharan Africa, where nearly one in every 20 adults is living with HIV, according to UNAIDS.

In developed countries such as Britain, new treatments have made the disease manageable while new legislation and public campaigns have gone a long way to ensuring people with HIV do not face discrimination.

But the number of new infections is still rising, particularly among the high-risk groups—gay and bisexual men and black Africans.

New diagnoses among gay men in Britain are at an all-time high, with one in 20 now infected with HIV—and one in 12 in London, according to the Health Protection Agency.

Butler is worried about a "second wave of HIV" among a generation of new young people who "think AIDS isn't a problem any more".

He said [HIV](#) campaigns have been "airbrushed" of the images of emaciated [AIDS](#) victims that scared many people into getting tested or wearing condoms, "and I don't think we're spending nearly enough on sex education".

"That's always a challenge for us—to keep it relevant and keep it immediate, and to keep them safe," said Partridge, who joined the Terrence Higgins Trust as its first paid member of staff in 1985.

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