

Disclosing as a Form of Activism

Dan Hartland, Founding Director of Saving Lives, talks about how people living with HIV talking openly about their status can help diminish the fear of stigma felt amongst many. This will, in turn, encourage more people to get tested, and ultimately save lives.

Saving Lives is an HIV awareness-raising charity which we devised with a simple belief: HIV testing is crucial in saving and improving the lives of those living with HIV.

In the 1980s, the only thing a mass media campaign could find to say about HIV was: 'Don't die of ignorance.' Now, with excellent drug regimes and fantastic support networks, we can say that awareness can set you free as treatment can offer a long and full life.

But a charity like ours is only as strong as the positive voices. We rely on advocates who are living with HIV to help us devise our messages and communicate the realities of today's HIV-positive people. We've benefited from the input of some fantastic individuals, who have featured on our website, talked about the importance HIV testing on the radio and appeared in television coverage of our campaigns. What they have said has been brave, eloquent, passionate and inspiring. But it has also been, more than occasionally, delivered on the condition of anonymity as advocates often request that photographs of them, and sometimes even their voice, do not appear anywhere in the campaign materials.

We respect these decisions, and we are so grateful for every bit of effort made in support of our work, but it also saddens us that it is still so difficult for people living with HIV to be open and honest about their status. Society has a long way to go. Stigma still exists and is a key factor in dissuading people from taking an HIV test. One in four people with HIV in the UK are unaware of their status as a result of this. This is why normalising the way we talk about HIV is very important.

It is naïve, of course, to imagine all prejudice can be eradicated – but Saving Lives are committed to ensuring it is much less pervasive, and entirely unacceptable in the public eye. Disclosure has a huge role to play in achieving this aim. It is precisely because disclosing is still such a difficult thing to do that it is such an important move to make. Only openness, solidarity and public advocacy may soothe the fear of stigma which is still felt amongst many.

Saving Lives' latest campaign sees Olympic athletes and Premiership footballers endorsing HIV testing in the UK for the first time. We hope this will have a real impact, not just on the rates of early diagnosis but on the tenor of the conversation surrounding HIV. And, as HIV-positive people speak out, we have faith it will become ever easier for more people to feel free to follow suit. Here are four personal stories from Saving Lives and Positively UK advocates in which they share their own experiences of disclosing or talk about their HIV publicly for the first time. We hope these stories will further encourage an openness and normalisation of the discussion of HIV, and, in turn, inspire you to get tested yourself or to consider your own disclosure to family, friends and colleagues.



THE POLITICAL ISSUE



Peter

Saving Lives

I have been undergoing treatment for HIV for some time but I only decided to 'come out' recently. I did this because I've been through so much that could well have been avoided if awareness about HIV was better. By speaking openly about my experience I hope I can contribute to the creation of a world where stories like mine won't be as common.

I probably became HIV positive in 2003 while in a stable, monogamous relationship. My partner suffered from persistent coughs and colds, as well as itchiness and a few other symptoms that ten different GPs in total couldn't explain. She had X-rays and was referred for bone marrow investigations but again and again, there was no diagnosis. It was only through our own research that we realised my partner should be tested for HIV. I was frustrated that, until this point, no doctor had suggested it. My partner

tested positive with a CD4 count of 28. She could so easily have died because of all those missed opportunities for testing.

I tested positive too with a healthier CD4 count of 450. But there was an abnormality with my liver function and I was diagnosed with cancer of the liver and recently doctors discovered a rare complication with my liver transplant: half the blood flow to my liver stopped, and half of my liver died. I'm now awaiting a liver transplant. Nevertheless, I'm coping.

I don't want other people to come as close to death just because of the widespread reluctance to test, amongst the public and, from my experience, doctors. There is a stigma around HIV that needs to be countered. This is why I'm speaking out – disclosure, simply talking about your own HIV, can help not just you, but others.

Disclosing as a Form of



Chris

Saving Lives

Early in 1986 I was diagnosed with HIV and told that I had just 18 months to live. I'd moved up to London in '79 and was the new young guy around town having fun. A lot of my close friends died within a few years of being diagnosed. I was emotionally very vulnerable so I decided to tell a few people at my church. One of those people was absolutely superb and, to this day, have supported me. But, sadly, another of the people had other ideas – and talked to the papers.

I found myself in The Sun, described as an 'AIDS-carrier organist' and photographers invaded my church. At

the time it was worse than getting the virus, I lost my job, my friends at my church shunned me and no one would shake hands with me. At that time disclosure was a very difficult thing to do.

Thankfully, by the end of the '90s perceptions of HIV improved and it became more accepted. But nowadays I worry it's becoming much more secretive again. HIV just needs to be talked about more. It needs to become part of everyday life – we can't hide away from it because it exists. Disclosure still requires great bravery but it has a big part to play in making things better.

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