

COMMENT

## **HIV: if we can achieve normalised testing we'll be helping to banish the stigma for good**

Evans, D.T. (2010) *Nursing Standard*

*As nurses, let's build on all the advances that have transformed care since the bleak days of the 1980s*

The first person I met whom I knew was living with HIV was a woman who wanted regular pastoral visits from a priest. At the time, I was on what was to be a ten-year break from nursing to fulfil my childhood desire to be ordained as a priest.

Due to the stigma of HIV, the woman was too frightened to see her local priest but I was based in the next parish. When I met with her, I found that, like so many people in her position she had questions and fears that she wanted help to address. She and her child were in accommodation for people living with HIV. Everyone there had their own stories; they were just human beings trying to make sense of life.

### **Bleak days of the 1980s, when the stigma of HIV/AIDS extended to healthcare**

That was 1988.

HIV was the biggest issue that touched me during my decade with the Catholic church. For one thing, it challenged my faith in organised religion. Why were so many millions of people living in fear of a virus? Why were so many societies and world religions hijacked by those who wanted to blame, to stigmatise and exclude? During this time, that kind of negativity came from many healthcare professionals too.

I left parish life in 1989 and returned to nursing, working on an HIV ward at St Mary's Paddington in London. Those days were bleak. HIV prevention often boiled down to condoms, sexual abstinence or 'fingers crossed, it won't happen to me'. Treatment was limited and experimental, more symptomatic than curative and focused on quality, end of life care.

### **When Princess Diana visited St Mary's HIV unit she chatted, held people hands – and did not wear gloves**

World AIDS Day 1989 is forever ingrained in my memory. It was the day Princess Diana officially opened the HIV unit at St Mary's. The 20-bed ward had four beds for general medical patients, so that when journalists phoned up asking 'which is your AIDS ward?' we could honestly say that this particular ward was a medical ward. That we had to take such precautions is a measure of how extreme the prejudice was at that time. Diana met everyone that day, person to person. She made eye contact, chatted, and held hands. She did not wear gloves.

A year later, when I was working as a lecturer-practitioner in HIV and AIDS at the Middlesex Hospital and University College Hospital London, I witnessed the princess's encounter with an unconscious man with end-stage AIDS-defining illness. She whispered in his ear to introduce herself, and then spent as long holding this man's hand and talking to him as she did with any of the conscious patients.

Princess Diana touched the lives of so many of us who met her on those HIV wards. She epitomised what we now refer to as the '6Cs of nursing', and with her human touch was so skilled in disarming HIV and AIDS-related stigmas. It is important to talk of 'stigma' in the plural, as there was more than one in relation to HIV. In the 1980s, some of the stigma related to it as a hidden, viral infection, with (then) unclear modes of transmission. There was also stigma related to the more visible AIDS-indicator conditions, usually with identifiable sets of illness signs and symptoms.

### **Understanding the case for early HIV testing and intervention**

My teaching about HIV today revolves around clear and proven methods of primary prevention, and the success rates in early treatment interventions – that's why testing is so important. Knowing how to prevent the acquiring or transmission of HIV is bolstered by practising [#ScienceNotStigma](#), as we say on Twitter.

Every healthcare professional should know that for infection to take place, there needs to be viral 'quality, quantity, and route of transmission'. Effective methods of prevention still include condom use, for many people, but now there's greater emphasis on combined methods, including early/regular testing, to [#KnowYourStatus](#), followed by immediate start on antiretroviral therapies (ART). These days, ART has a role in prevention as well as treatment.

Prevention also includes pre-exposure prophylaxis (PrEP); postexposure prophylaxis (PEP) and treatment as prevention, or TasP. 'We should all be trying to normalise HIV testing' Starting antiretrovirals early means they are so effective, for most people living with HIV, that the person goes on to live a long and healthy life that we could have only dreamed of in the 1980s. Once the viral load (VL) is undetectable, then 'Undetectable Equals Uninfectious' (U=U) or, as the Terrence Higgins Trust campaign proclaims: [#CantPassItOn](#).

### **Some nursing practices suggest prejudice persists**

Probably the biggest impact of stigma remaining today is the fact that HIV is hidden, unspoken. HIV hasn't gone away; people just talk about it less than they used to. Examples of the same old isolationist prejudice persist in healthcare, such as putting people with HIV into single rooms unnecessarily, double-gloving, or using HIV markers or identifiers on clinical notes. Any nurse who thinks this is right needs to update their HIV awareness and practice. Our [code of conduct](#) clearly says we must 'challenge all forms of discrimination' as we 'prioritise people'.

Probably one of the best ways nurses can make a difference across most fields of practice is to promote HIV awareness. In particular, we should all be trying to normalise HIV testing –

shifting it to become 'opt-out', as in antenatal services.

This one action means you get the multi-professional team talking about HIV. Talking about it would help de-stigmatise HIV and reduce the number of 'late presenters', who have poorer outcomes. By encouraging HIV testing you would improve the quality and quantity of a person's life, as well as preventing them from passing the virus on.

### **Awareness of AIDS-defining illnesses**

Equally, getting to know the various AIDS-related illnesses (such as tuberculosis) could lead to more proactive and opportunistic HIV testing. Each time TB, or any other AIDS-defining illness is a possibility, it is a good idea to promote HIV testing.

In general practice, nurses and doctors could implement testing with all new patients, or discuss it when people are in travel consultations, especially when they are planning to go to countries with higher HIV prevalence and where there is a chance they will be having sex. The more people who are diagnosed early – and given immediate access to treatment – the greater their potential to live long and healthy lives. This can also help us to reduce new transmissions to zero. [#LetsEndIt](#)

### **HIV nursing has come a long way and there is so much we can do to build on that progress**

These days I begin teaching sessions on HIV by saying that although there is still no vaccine for HIV and no cure for AIDS we are in the most positive position since AIDS was first labelled back in 1981. This is true – despite the terrible conditions faced by many people living with HIV and AIDS around the world.

Affluent countries have benefited most from the medical advances of the past 30 years. A huge issue now is improving access to prevention and effective treatments. But at least there is hope – in the 1980s there was none.

UK nurses in most settings have an important role to play in building on the progress that has been achieved and overcoming the remaining stigmas of HIV – and not just a role, a duty. Go back to [your Code](#), read the opening section on Prioritising People, and consider each line in the context of HIV. It's all there.

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### **More from David Evans**

Evans DT, Dukes M (2018) *Current approaches to HIV prevention, treatment and care*, **Nursing Standard** <https://www.ncbi.nlm.nih.gov/pubmed/29923694>

### **HIV Matters! Foundations for practice. Brief teaching videos and resources**

<https://spark.adobe.com/page/zUbXKlp2vLiIB/>

## **Meeting Princess Diana and other stories of HIV client care**

<https://davidsmemoirs.wordpress.com/2016/08/25/blog-post-title-2/>

### **Resources**

Avert 'Global information and education on HIV and AIDS' [www.avert.org](http://www.avert.org)

National AIDS Manual [www.aidsmap.com](http://www.aidsmap.com)

National AIDS Trust [www.nat.org.uk](http://www.nat.org.uk)

Terrence Higgins Trust [www.tht.org.uk](http://www.tht.org.uk)

UNAIDS [www.unaids.org](http://www.unaids.org)

WAD2019 Campaign [www.worldaidsday.org](http://www.worldaidsday.org)