



Balancing on Wheels of Hope

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Previous articles

include [HIV/Aids: a war on women](#) [1] and [World Aids Day: a message](#) [2]

"Life is like riding a bicycle - in order to keep your balance, you must keep moving". Albert Einstein

In a fleeting moment whilst there is something trendy about being a "50-something woman", I am happy to report that I have just been for a wonderful relaxing 3-hour bike ride, 26 miles and back along our local estuary. Herons stalking, gulls crying, swans aslurping, children laughing and the hedges overladen with succulent blackberries on a glorious Indian summer Saturday. I may not have Dame Edna's pheromones but I certainly have nicely developing thigh muscles, and also have a few more miles - and smiles - in me too. "So what", you may ask - "nothing different to many 50-something women" but when I add that I have also been HIV-positive now for over 20 years, people begin to realise that this virus isn't what most of the public assume that it is and that most of us still lead [fully](#) [3] productive lives, both mentally and physically, to the best of our abilities and thanks to the wonderful drugs that I have now taken for the past 9 years. Why is it then that still in the UK, although there are around 25,000 women living with HIV, you aren't aware of the ones living in *your* neighbourhood? That is because the stigma and [discrimination](#) [4] still faced here in the West by so many of us - men as well as women - affect our mental health so deeply we are driven underground, deeply fearful that if our health condition is known we will lose our jobs, be ostracised from our neighbourhoods, have our children bullied and rejected at school, have our cars daubed with indelible paint and [worse](#) [5]. I have written here before of the risks of the legal profession trying to impose punitive laws on people with HIV, both here and abroad, in a vain attempt to curb this pandemic through resorting to the statute books. This time I am looking at the role of the health sector - again both here and globally.

In Southern Africa more staff are lost from the health sector annually through HIV- and AIDS-related illness (mostly TB) and deaths than they are able to recruit. This is largely because these staff too are so terrified of disclosure to their colleagues and bosses and the resulting loss of face that they prefer to slide into the shadows, lose their jobs and die rather than risk going public. In Uganda, a recent study reported that *"mortality data for a cohort of Ugandan doctors [in Uganda] showed that, of 22 doctors who died, 11 died of AIDS, and 5 committed suicide because of a known or suspected HIV diagnosis."* In Papua New Guinea, former nurse and now AIDS activist for the Australian Government, Maura [Mea](#) [6], experienced the death of her first child from lack of health care, the death of her second from receiving a live polio vaccine when he was HIV positive, and then the forced abortion of her third and a coerced sterilisation. *"They did not see me as a person. I felt angry, I was scared, I was confused."* She has a lot to say about the attitudes not only of her colleagues but of the whole health profession in the context of HIV.

Here in the UK also, I know several HIV positive health workers who dare not share their health condition:

"I was working as a psychiatric nurse and we had an HIV positive patient. The nurses working with me were really worried about looking after him, and they made some really negative comments...It made me feel so scared...What if they knew about me? I just couldn't be open about my status at work."



Another friend, an anaesthetist, was recently working in Essex. She saw that if theatre staff knew that a patient was known to have HIV they would avoid being on duty for that operating shift.

These attitudes are not grounded in science, since according to WHO, "*...less than 10% of the HIV among health workers is the result of an exposure at work...*"

Indeed, exposure to hepatitis, for example carries far higher risk to health staff than does HIV, yet thankfully hepatitis and those with hepatitis have so far escaped the stigma associated with HIV.

Even though needle-stick injuries should of course happen nowhere, and the rigorous enforcement of procedures, such as correct disposal of sharps, should ensure this, by far the greatest percentage of HIV transmission to health care workers is through sexual transmission outside the workplace - or even through sexual harassment at work.

Of course, female health staff (who form 80% of the world's health workforce) who are the most over-stretched, underpaid and under-trained sector of health services, don't need to be told this. In a study by Liverpool School of Tropical Medicine and partners in [Kenya](#) [7], they noticed that only 25% of health workers accessing drugs to prevent HIV after a needlestick injury were female, despite 72% of the staff being female. When asked why, the female staff responded: "We are at risk of HIV every night in our marriage beds. What difference does the odd needlestick injury make to this;

Sadly, in the health sector perhaps even more than in others, to be a staff member who is sick is somehow to cross a silent line between "us" the professional experts and "them" the patients who seek "our" support. This has been well documented in many [contexts](#) [8]. It somehow rattles and unbalances the status quo, as if a game-keeper has suddenly turned poacher. All the worse then when the chronic illness may have been sexually acquired and therefore churns up all the moralistic attitudes held not just by many in the medical profession but by society at large. It is understandable therefore to hide collectively behind the excuse of a needle-stick injury and to "safely" blame the patients for bringing HIV into the health centre. But the evidence just does not match up to this excuse and health authorities too need to realise that they, their staff and their families are just as much exposed to the storms of life that touch us all when it comes to sexual health, divorce, reproductive crises, [alcohol](#) [9] and other drugs use, mental health issues, gender violence - and yes, HIV also.

The story isn't all bad. In some wonderful projects around the world, health staff have joined together with people with HIV to shape a new balance and form new practices towards people with HIV. The [Mothers](#) [10] to Mothers programme, at ante-natal care centres in several East and Southern African countries, have trained women who themselves tested positive during pregnancy at these centres, to become paid mentors to other pregnant women, newly diagnosed, to guide them through the initial shock and terrors of their diagnosis. In Swaziland, the [Wellness](#) [11] Centre is offering a place of holistic support, care and treatment for HIV positive health staff, in order for them to regain the self-confidence which an HIV diagnosis smashes out of everyone, and to keep them in work. In the US, lawyer turned HIV advocate, Heidi [Nass](#) [12] works in a health centre in Madison, Wisconsin, supporting women with HIV by revealing to them her own diagnosis. In Uganda, one of only two openly HIV-positive woman doctors I know globally, Lydia [Mungherera](#) [13], is doing wonderful work with her award-winning Mama's Club, providing psycho-social care and support to young HIV positive mothers - and fathers too now - across Uganda. And in London, Jane Anderson and colleagues at the [Homerton](#) [14] Hospital have set up a great holistic health centre for women with HIV.

These examples just go to show what can be done by the health sector globally to turn the tide of public opinion that is so militant against people with HIV. With the right approach to their own staff who are sick, with inclusion of HIV positive women in the whole process and with the recognition that health workers too are human beings who need love, care, respect, support - and *hope* - from *within* their own profession, we can all move forward. Without such global measures health staff with HIV will continue to die and numbers of people with HIV will continue to rise.

In London this week the [Sophia](#) [15] Forum will be meeting to address these issues with health workers from across London, in a meeting aptly entitled "In sickness and in health: Women and HIV



in 2009", with lead guest speaker Peter Piot, formerly Executive Director of UNAIDS, and Moderator Sue MacGregor.

As for the cycling, this is just the start of seeing how far this 50-something woman can go with this bug in my body. I will keep you posted.

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[12] <http://www.thebody.com/content/living/art43373.html>

[13] <http://www.icw.org/node/318>

[14]

<http://www.homerton.nhs.uk/our-services/sexual-health/csshh-centre-for-the-study-of-sexual-health-and-hiv/>

[15] <http://www.sophiaforum.net/index.php/page/Home>