

Dr Alice Welbourn, author of Stepping Stones

Introduction: Dr Alice Welbourn lives near Exeter in Devon, and usually describes herself as a trainer. Which she is, but she is also a writer, a public speaker, an HIV activist, and a mother. She has a D Phil in Anthropology from Cambridge University. She wrote the Stepping Stones manual in 1994/95. She has had a long association with the International Community of Women living with HIV and AIDS, and is a frequent speaker at international meetings and conferences. She is deeply involved in networking with users of Stepping Stones worldwide. **Tony Williamson.**

Alice Welbourn: I also of course want to reflect on the extraordinary vision and dedication of Glen Williams, and indeed all of the Strategies for Hope team over the years.

I would just like to reflect a little bit on what HIV means here also in Britain, because as you heard, my husband Nigel, who used to be one of the Strategies for Hope connectors in ActionAid, and I used to live here in Thame. And I was diagnosed with HIV in 1992, and so came to be under the care and support of Tim Peto here in the JR, and I still come here every six months or so to see Tim, and we have turned into good friends over the years. When I was first diagnosed in '92 it was completely devastating. We also thought I was about to drop down dead within weeks, and not only was I extremely fortunate in having Nigel there to support me, and Tim, but I also came round the corner here, in Blue Boar Street, to OXAIDS. Now OXAIDS nowadays is Terrence Higgins Trust, and I can't tell you what a beacon of light and support OXAIDS was in those early days. And we met the most extraordinary people there who were also struggling with this virus. I remember Kim, who was a young woman and injecting drug user, who'd come down from Glasgow, had managed to escape from the cycle of addiction to drug use by moving down to the south, having left her friends and family behind, and wanting to pursue her love of looking after horses: only to find that that legacy remained in her body, in the form of HIV. And we saw her gradually fade away and die. I remember Dave Swales, who was one of the key movers and shakers of OXAIDS in those early days - what a wonderful man he was, and he also faded away and died. There were wonderful young men who were gay, and had experienced all the suffering of homophobia, and growing up faced with that homophobia from their own families, and then faced also with the challenges of discovering that they had HIV, and having to cope with that. And those men also dying. And I remember, finally, there were also many Africans studying here in Oxford, who daren't even meet together. A friend, and I, who was a nurse who was HIV-positive - we set up a women's group, and there were African women here from different countries, most of them studying here in Oxford, who didn't dare to come to our meetings for fear that they might meet another woman from the same African country, for fear that the message might get back, through friends and family, to their own families in Africa. And so we used to visit them in their homes around Oxford. And this is all here in Oxford. This was the early nineties. And I remember getting the stage where I actually couldn't go to Dave Swales' funeral, because it just felt too close to the bone. It was one funeral too many that year. And so, to me, being back here, just literally round the corner from where we used to have our support meetings, feels especially emotional, and a personal reflection for me.

And what an incredible difference it made when the anto-retroviral drugs started to appear in the mid-nineties, and that peculiar Lazarus effect of remembering one particular Caribbean woman, who hadn't come to the previous meeting of our support group the month before, and we all of us silently feared that perhaps we weren't going to see her any more - and our utter delight and amazement when not only did she appear, but she came striding through the door, saying 'I've just been horse-riding!'. And it was just so incredible because she had started to take the drugs, and it had made such an effect, and I also remember the wonderful hospitality of the former Bishop of Oxford, the Reverend Richard Harries - and I think his wife

is here with us tonight - how kind they were in offering us regularly their beautiful house in North Oxford, and their gardens, as a safe haven both for us who were HIV-positive, and also friends and family, to relax for the day, and to feel safe, and supported and loved.

So I just want to reflect on all of that because that has been happening here, in this city, over all of these years. And yet what's so tragic is that it's still all so hidden. Winnie Sseruma, who's here from Christian Aid, in the audience with us here this evening, and I, we're two of over 30,000 women who are HIV-positive here now in the UK, and yet still there's only a handful of us - around 20, 30 or so - who dare to be open about our status. There are so many women who would so love to be open about their status, but particularly if they have children, they want to protect their children from that stigma and discrimination, which is still so desperately strong here in Britain, despite having the drugs. So it's just so tragic, what is still going on, despite the fact that people like Winnie and myself, and Gideon - you can see how fit and healthy we are. You'd never thinking walking down the street that we too have been living with HIV for well over 20 years. And yet those drugs can make such a difference, and it's the right of everybody with HIV to have fully productive, respected and dignified lives.

So I have been asked this evening if I might say a few words to enable us to remember the lives of all those who have gone before. It's customary in this kind of moment of thinking to light a candle. Unfortunately, because of health and safety, we can't do so here. But we'd like to suggest that you all might like to think, on World AIDS Day, which is coming up shortly, of lighting a candle in your own homes, and if you have friends or visitors on that day, to share with them why you are lighting that candle - to think about the millions across the world who have already died, the millions who are still contracting HIV every day, and the hundreds and thousands, even in this city, who have either had HIV and have died from it; their families; their friends who remember them; and all of those wonderful people like yourselves who are working on HIV in so many different and significant ways. So I would like to suggest now that we have a minute's silence, and just think together about all those millions of people out there, all of whom need our respect, our solidarity, our support.

(Minute's silence.)