

**‘The kids
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have been so fortunate – in their GP or their partner.

We met my consultant the next morning. He gently shared all he knew about the progression of the virus, the definitions of HIV and of AIDS and so on. I was in shock and couldn't take anything in, but my partner, being medical, did – and explained it all again later.

One problem with HIV, as with chlamydia, is that it can lie dormant for years without symptoms. The specialist told us that I probably had at least 10 years to live, but I was convinced I would be dead in six months. For the first and only time in my life, I contemplated killing myself – I felt I'd brought shame and burden on myself and my family.

It was a harrowing time. I was told that if I were to go ahead and have the baby, there was a strong chance one of us would die. We opted for a termination. The obstetrician was exceptionally gentle, but losing the baby on top of my diagnosis left me grief-stricken for years. Nowadays, with the right drugs and a Caesarean section, the chance of mother-to-child transmission is less than two per cent.

The next few months were a blur. I guess your mind shuts down, focusing on day-to-day practicalities. I do remember telling my partner that I didn't expect him to stay with me. To my immense relief, he told me that he wouldn't dream of being anywhere but by my side. It seemed miraculous that I hadn't passed HIV on to him, and we have taken care to use condoms ever since to be sure.

Nonetheless, I felt scared, confused and alone. My physical symptoms at the time were non-existent, so we told only a few close friends. With HIV you fear you, your children and family may be rejected. Susan Sontag once described HIV as 'the new cancer'. Thankfully, most people with cancer now can talk openly about their illness and find support. I hope one day the same will be true of HIV.

At dinner parties I would burst into tears in the loo after an oblivious guest said something 'funny' in relation to AIDS. People can be so ignorant about anyone different from themselves. It was as if some people deserved to get HIV – and as if they themselves were immune to such a virus.

Most of the close friends we told in those early years were extremely supportive. But a few were not. I don't blame them for that. The stigma around HIV was so huge – it was too much for them to cope with. For many years I referred to my HIV as 'the gremlin on my shoulder' – always there when I was with people I hadn't told. I became rather withdrawn, but the weight of my secret meant it was easier not to socialise.

In those early years I would often visit others with HIV – extraordinarily courageous people I grew to respect and love. I'd attend their funerals, where no one mentioned why they'd died. Before the new anti-retroviral

drugs arrived in 1995, it was terrible how many people slipped downhill unnoticed, then were gone. The dramatic increase in recovery rates since has been called the 'Lazarus Effect'.

In 2000, my immune system deteriorated and my doctor recommended I take these drugs, too. I'd had three nasty shingles attacks between 1995 and 1999, a sure sign that my immune system was damaged, but otherwise I still felt well. I even swam 100 lengths for Shelter the same week I started the drugs. They keep me working, hiking, swimming, living. Some people get bad side-effects, but so far I've been lucky. I take three drugs religiously every day, and will need to for the rest of my life.

Since my diagnosis, my work has shifted to curbing the spread of HIV internationally, through supporting people to develop their relationship skills with partners and families. One reason why HIV has spread so effectively is because we find it difficult to talk about sex in our relationships. With a team of largely African colleagues I developed a training workshop called Stepping Stones, which supports communities in working out the issues that drive this global pandemic.

Policy-makers make simplistic assumptions that by following 'ABC', ('Abstain, Be faithful, use Condoms'), people can protect themselves against HIV. But what good is abstinence to a wife if her husband threatens to hit or divorce her if she won't have sex with him? Or if she wants to have a child? What if you are faithful but your husband has other partners? How do you insist on condom use in a marriage bed?

While science has improved our physical health – in the West, at least – the stigma and discrimination are still terrible. I didn't 'go public' about my status until five years ago because we were fearful of how it might affect the kids. In fact, most of us who know our status dare not share it with friends and colleagues for fear of the fall-out. Of the 20,000 women in the UK with HIV, only around 20 speak publicly about living with the virus. It's ironic and tragic, as studies show the best way to educate people about HIV prevention is for them knowingly to meet an affected person in their circle.

I also decided to go public because a lot of HIV 'experts' clearly had no idea what it is like to be living with the stigma. People have mostly been supportive, which is a huge relief for my relatives, though the older generation still find it tough and hope others won't notice my name in the papers. But 'Mum's secret illness', which thankfully none of the rest of our family shares, has stressed our children. Over the years they have endured endless sick playground jokes about 'gays with AIDS', and felt exposed for not laughing too. They've had to grow up so fast, which saddens me. But we admire them because they understand more than most kids their age how precious and challenging life can be.

For now, I remain fit and well. I'm approaching 50 and am amazed how lucky I have been. I think I have a good few years to go, but I try my best to appreciate each day left to me. This virus has taught me so much about life as well as death.

How to help

Alice volunteers for The International Community of Women living with HIV/AIDS (ICW). She says: 'Over 15 million women have HIV. Last year, over one million died because they couldn't get the basic drugs to keep them alive, leaving their families and communities devastated. Those of us involved with ICW have a dream that one day everyone who needs these drugs, which can now cost less than 50p a day, will have access to them.'

- Visit icw.org to make a donation towards helping women with HIV/AIDS.
 - SOPHIA is a new information forum about women and HIV in Britain and internationally. Visit sophiaforum.net.
- HOW TO GET HELP** Are you a woman living with HIV? To talk to another woman with the illness, call Positively Women on 020 7713 0222.

Hair and make-up: Sue Thompson