

## **Blood**

If I meet someone new, let's say at a dinner party, and that person asks about my family or my childhood then I test how little I can get away with saying. This works exceptionally well if I'm sat next to an extroverted, chatty, person who, if I make the right sounds from time to time, will happily fill in the gaps. 'I'm told you're a poet; that must be difficult. I mean how does anybody make any money doing that? But I hear you have a book and you're doing really well so you must be doing something right?'. It is fascinating to note how one-sided an exchange can be and how few words you can speak and still be in a conversation with someone. If I'm feeling particularly mischievous I make things up. The trick is to try and keep a straight face. If you can say something with a straight face even the most incredulous of sceptics will be taken in for a moment.

Sometimes I don't have to fabricate anything; someone will make an assumption about my life and I simply won't correct them. So when they ask where I grew up and I tell them, and then they imagine me living there with my parents, it is easier to stick to what they believe to be true than to explain myself further. Talking to someone for the first time is rarely the right moment to share the most painful facts of my life but the things that come up when two people are trying to get to know each other, when both parties are attempting to appear breezy and casual, are very difficult for me to talk about because, if I tell the truth, there is no way of making that truth *light*. I can't, if someone asks about my mum and dad, say to them 'they both died when I was kid' or I can, but if I do, that immediately pushes the conversation in a certain direction. Parents are not supposed to die so early in their children's lives and so sharing one of the most basic truths of my life means causing other people discomfort. 'How did they die?' Is a natural follow-up question but, in this country at least – where restraint is an

art form – nobody ever asks me that, though their facial expressions sometimes do. Faced with a choice between letting someone I don't know believe I have lived a life I have not lived, and watching their face change as they struggle to know what to say or do, I more often than not choose the lie.

It is the question of how my parents died that brings me to the subject of blood. If I'm in a forthcoming mood and someone asks me directly, 'how did your parents die?' I weigh up whether I can be completely truthful in response. If I'm feeling especially open I might say that my parents died from 'a blood condition' which takes care of the salient points but is mercifully vague. What I rarely say is that my parents died from Bronchopneumonia because they both had HIV. I don't elaborate and say that they died because HIV impedes the function of white blood cells; the cells that otherwise would help the body protect itself.<sup>1</sup> I don't go on to explain that in Zambia, where I was born, 'the prevalence of HIV' among adults is thought to be somewhere between 12% and 20% depending on the region.<sup>2</sup> I don't say that Zambia is a country of around half a million children who have lost a parent or both parents to the virus.<sup>3</sup> The reason why I don't, is shame. There is so much stigma, lots of which is racialized in deeply problematic ways, and such a dearth of understanding around HIV that I don't feel able to say what is true without incurring judgement.

Perhaps my fear of judgement is something worth challenging, and people are more understanding than the wider culture would have us believe, but the risk involved in moving beyond that fear still feels significant. It has taken a long time to let go of the

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<sup>1</sup> Terrence Higgins Trust, '[The Immune System and HIV](#)'

<sup>2</sup> UNAIDS, '[Zambia HIV and AIDS estimates \(2015\)](#)'

<sup>3</sup> Ibid

shame enough to tell even those closest to me about the effect HIV has had on the course of my life. I knew my father had the virus and died because of that because my mum explained this to me when she felt I was old enough to understand. I did not realise when my mum started to get ill that it was with the same virus; she never explained to me why she was losing so much weight or why she needed so many tests when I came with her to the hospital. As I understand it now, it's not something my mum accepted. She refused treatments that might have kept her alive. Did she do this out of shame? She is not here to answer that question and I can only guess at what she was feeling in what must have been an extraordinarily painful time for her. What I know now, is that if she did feel such shame that she was unable to accept her diagnosis, and if shame is part of the reason she refused help, then I have to knock shame on its head. I would rather nobody knew what it was like to lose their parents as a child; to not have their parents with them in their most formative moments; to feel a loss even in the midst of joy because their parents are not there to see it. That, however, is not the life I've lived and those who really know me, know at least that much about me. What I have always been too scared to do is let many people know more than that.

What my mum couldn't tell me as she faded from life, she left to my aunt and uncle to explain and, after taking some time to let me adjust, to grieve, my aunt took me aside one day and asked if I had ever been curious about how my mum had died. In the way she phrased her question there was space for me to say 'no' and then perhaps she would have had to bring it up another time but, as it happens, I said that I was curious; I did have questions. I am struck afresh, in writing this, by my aunt's capacity to defer a conversation until the right time, how she must have known what she had to tell me would be difficult to hear. She looked at me then with the same calm expression as she

had when she sat with me before school one day, not long after my thirteenth birthday, and told me that in the early hours of that morning my mum's lungs had collapsed and the medical staff had been unable to revive her.

After this second, more detailed, conversation with my aunt, I became obsessed with the notion that I had HIV, too. It was possible to pass the virus from mother to child, through the blood, wasn't it? What if I did have it and it had been going untreated all this time? I realise now that this fixation was my first attempt to come to terms with how I felt about the manner in which my parents died and, beyond that, how I felt about the fact that the only thing many people know about Zambia, if they know anything, is that it has one of the highest HIV infection rates in the world. I felt angry that my family wasn't an exception to that statistic, that it was not only my parents but their friends, neighbours, and family members who had been affected. How could I hold that much shame in my body? I had to find out if I had the virus, too, and put the questions in my mind to rest.

It is important for you to understand at this point that I have, for as long I can remember, been afraid of needles. When I say afraid I mean that sometimes my body spasms unexpectedly when images of needles pop, uninvited, into my head; when I say afraid I mean once when I was four or five years old, when I was taken to the doctor for booster injections, I took one look at the needle that was being primed for contact with my flesh and I ran: out of the room, out of the medical centre, and a good way down the road before anyone was able to catch up with me. I was caught at the point when I was trying to decide if it was wise to cross the road on my own.

When I finally worked up the courage to be tested for HIV I was an undergraduate, studying for a degree in English Literature. The university had been very conscientious about letting us know that it had a free, easily accessible, confidential, walk-in sexual health service. I took myself there early one morning and sat in the waiting room trying not to catch anyone's eye or mentally speculate as to why they were there. If I didn't do it to them, I reasoned, they wouldn't do it to me. In time my name was called and I was ushered into a room where a doctor asked me some questions. Was I sexually active? I was not. So what had brought me there? I explained. For the first time I was saying the words aloud to someone else. I was told it was unlikely that I had HIV but they took my blood and sent it off to be tested.

As I walked home I thought about what it would mean to get the results. I knew the doctor was right and that I was unlikely to have HIV but I didn't know what to do if I did. Would I tell anybody? I walked the long way home and when I finally got back to my room I sat down against the wall — a woodchip wall painted some variation of white which harboured a nest of ants. I sat against the ant-infested wall and waited for my phone to ring. To pass the time I ran all the possible outcomes round my head in a fruitless loop. I didn't tell anyone what was going on because I didn't feel able to explain. So, I sat in that room on my own conducting my unscientific study of time and its relative speed. After what felt like several hours but was, in all likelihood, about ninety minutes, somebody called to talk through my results. I was not HIV positive nor, predictably you might think, did I have any other STIs. Until I had that confirmation there was always the slim chance but getting that confirmation gave me perspective. Taking the test was the first step in talking about how HIV has affected my life. It opened a space for dialogue that I had been shutting down.

It is almost thirteen years since that day and it is only now I'm starting to see that what I have been calling 'a blood condition' is nothing to be ashamed of, that letting go of the shame I have around it lifts a heavy weight from my life. If, and only if, I can accept the things that have happened, then I can be truly present; then when someone asks me about my parents I can tell them that my parents met at university; that they fell in love; that they died when I was a kid; that it hurts a little everyday; that even though it hurts I am still here and so long as I am I try not to let that pain be all that I can feel.