

Common threads

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For women living with HIV, the decision to have children can be one of the most difficult choices they make. For women who are diagnosed HIV positive at the time they are becoming mothers, those decisions can be especially urgent and confronting. In this extract from her new book, KARALYN McDONALD shares the stories of several women who have dealt with the twin realities of pregnancy and diagnosis.

Motherhood is at the core of many women's identities and some women, when first diagnosed, believe or are told that they should not or cannot have children. This is both devastating and incorrect. As revealed by the stories in Common Threads, many women do go on to become mothers. For most women becoming a mother is a very considered and sometimes fraught decision. There are many choices to be made when a woman decides to have a baby above and beyond those of other non-positive mothers. This includes how to conceive as well as treatment and care issues for both mother and baby. These stories raise many of the complex issues faced by HIV-positive women.

Diagnosed HIV positive and pregnant at the same time

Some women are diagnosed HIV positive during the routine antenatal bloods when they first discover they are pregnant. This is an incredibly devastating experience and many women find themselves in the terrible position of having to decide whether to proceed with their pregnancy or to terminate in a very short space of time. The most important thing to remember is that it is your decision and you deserve support in whatever decision you make. It may help you to speak with another positive woman who has been through a pregnancy. Alternatively seeking counselling and finding a doctor who is knowledgeable about HIV and pregnancy is particularly important.

In the past, women were often advised to have terminations because of the uncertainty surrounding the rate of mother to child transmission, the impact of pregnancy on the woman's health, as well as the mother's own life expectancy.

Denise discovered she was pregnant and diagnosed with HIV at same time in 1987:

The doctor said, 'Well you've got to have a termination'. Now I say that I made the decision, but I was greatly influenced ... The doctor said to me, 'You've got a six-year-old son, who's going to look after him? You're going to get sick, your baby may be sick'. And I remember standing in the corridor [and asking], 'Isn't there another woman in the whole of Australia who's ever been in my situation?' And the doctor said, 'Oh, not that we know of'. [I was given] an [information] sheet about women in Africa and I can just remember thinking to myself that I couldn't connect that situation with my situation and I had like zilch knowledge about HIV. It was a really traumatic experience and I remember crying heaps.

After undergoing numerous tests to try and get to the bottom of her unexplained illness, Sophie returned to her doctor for the results:

I came back on the Saturday morning to be told that I was HIV positive and the reason I was sick was that I was pregnant, but don't worry about that because [the doctor] had already arranged for me to have a termination ... The doctor said to me that he couldn't really do anything for me ... He had no proper training for HIV ... and that I should go to a different clinic that specialised in HIV.

So I went to this clinic and the doctor there told me that there was no way I could have children. So I went to a girlfriend of mine that's HIV, and she told me to go to a particular hospital, because there was a female

counsellor there ... I found the counsellor very, very good and she referred me to the Paediatric aids Unit at the Children's Hospital. I went there and it was the biggest eye opener, because its theory was no I didn't have to have a termination. I found the staff there awesome – they were really, really good. They went through all the pros and the cons – I had only recently acquired it, my T-cells were better than the average person's and my health was just A-1 ...

I'd booked for the termination but I couldn't go through with it ... Then my daughter was born and because I was so uneducated the doctors used her as a guinea pig. They pushed her, they poked her, they jabbed her. Luckily she was negative.

Even women who have been diagnosed recently sometimes face the difficult decision whether to terminate or continue with their pregnancy.

Olivia is 32 and was diagnosed in 1998:

It was just a random pregnancy test and the doctor asked me if I wanted an HIV test and I just said, 'Yes,' not thinking anything of it and, of course, that came back positive. My first thought was that I'm going to die and then I thought I was not going to go through with the pregnancy.

I think I only had two weeks to organise everything if I was going to terminate the pregnancy. I only found out I was pregnant around the 10-week mark. When my husband and I went in for a scan the doctor actually said that my uterus was bigger and my dates were wrong – that's when we found out it was twins. And for some reason I thought, no I can't do it. It shouldn't have made any difference, but having twins it did. So I went through with [the pregnancy] and then I was put in contact with another positive woman who also had twins.

Mary was diagnosed when she was 13 weeks' pregnant:

I asked the doctor, 'What about the baby? Does it affect the baby?' He didn't know. He didn't know anything ... I knew the time was coming short to have an abortion – I don't agree with it, but I knew that time was coming up. So the day I found out I had my little cry for a couple of hours and then I went to the phone book, big initiative! I looked up a clinic that deals with HIV and I went down the next day ... and I had a blood test – my bloods done the first time. My [viral load](#) [1]A measurement of the quantity of HIV RNA in the blood. Viral load blood test results are expressed as the number of copies (of HIV) per milliliter of blood plasma. was 3000 and my t-cells were 880 ... The specialist I saw put me on medication and I went down to undetectable and huge – 1300 t-cells. And I was like that for my whole pregnancy. [I was given] the choice to have a caesar or labour, but I didn't want to go through the pain of labour.

Diagnosed HIV positive just after the birth of your baby

There is also a lot to think about if you are diagnosed just after the birth of your baby. Your baby will also need to be tested and if you're breastfeeding you will need to wean your baby to prevent the risk of transmitting HIV via breast milk.

Sarah's daughter was six weeks old when her partner called her and told her that he had HIV.

I was sitting on the couch breastfeeding my baby, she was about six weeks old, and the phone went and it was her dad ... He told me he had AIDS and that I needed to get myself tested and possibly the baby and that he ... was going overseas to die and that was it. He didn't even come to see me in person ... So I just lost it ... I suppose I went into panic mode ... I was just losing it crying and my Auntie said, 'We'll get on the phone'.

The baby's father had given me the number of the counsellor at the hospital – he gave me her number and said to ring her and hung up on me and that was it ... So I ended up ringing her and losing it on the phone ... she didn't realise there was a little baby involved. So I informed her and she said, 'We virtually need you in here straight away if you can'.

So I had my test done that night and then my biggest worry was [my daughter]. I said, 'How do you pass it on to your baby?' [The doctor] said, 'It could have been done at birth ... it could have been done while she was in your womb or breastfeeding'. And because I was on the couch breastfeeding when I got the call I was a mess and I didn't know what to do there and then. Should I keep breastfeeding my baby? Should I stop feeding her right now? There was no preparation.

The doctor said, 'Although we deal with HIV we couldn't really tell you whether you have to stop now or whether another feed or two is going to...' They really didn't know a lot about that side of it. So I ended up ringing the hospital where I had Lila and the midwife didn't know a great deal, but she said, 'If it was me I probably would stop'. From the fact that it is an unknown and I was just feeling very lost as to whether —you know – it was too late? Had I already passed it on to her? Is another feed going to kill her? ... Would she be upset not being on breast milk, like cut off right there and then, that minute? I ended up stopping and my brother ran down to the chemist and got me some formula because she was due for a feed while we were waiting for results.

So I found out I was positive. That was pretty hard ... I know everyone thinks it can't happen to them, but when I first had the blood taken I had this feeling that I didn't and then to suddenly be told that I did; it was a big shock and I suppose it is for anyone. My biggest fear was then Lila. I didn't give a shit about myself. Her father and I had got ourselves into this situation but she was an innocent in it all and I was feeling very angry and upset with both him and I – that we may have passed it onto our daughter. It was pretty scary and then the doctors informed me that it would take six months of testing before we would know that she was in the clear, and I lost it again. That was the hardest six months of my life.

Common Threads: Women's stories of pregnancy, parenting and living with HIV is available from your state [PLWHA](#) [2] Person (or People) Living with HIV/AIDS. organisation, or by contacting [Positive Women Victoria](#) [3] on (03) 9276 6918.

Names and other identifying details in this story have been changed. Images from Common Threads by Cat MacInnes.

- [personal stories](#)
- [Positive women](#)
- [pregnancy and childbirth](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/416>

[2] <http://www.napwa.org.au/glossary/term/119>

[3] <http://www.positivewomen.org.au>