

Women & HIV

Dr . Kirsty Machon
& Heather Ellis
Positive Women Victoria

“The treatments, we've got are so effective and they're such a life changer and let people live long, happy, healthy and productive lives”



Transcribed directly from MOGCAST Episode 28. Listen here:

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“Hello and welcome to Women and HIV. My name is Doctor Kirsty Machon and I am the Executive Officer of Positive Women Victoria, an organization in Victoria funded to provide peer support and advocacy to women living with HIV, and I will be joined in this podcast by Heather Ellis.

Before I start, I would like to acknowledge that Heather and I are both recording from the traditional lands of the Wurundjeri people, and we pay our respects to their elders, past, present and emerging.

Positive Women Victoria is an organisation funded principally by the Victorian Department of Health, and we have a membership of about 421 members and clients from 56 countries around the world. Around 60% of our membership has been born overseas, with Zimbabwe and Thailand being among some of the countries with larger proportion of members and Positive Women Victoria was founded over 35 years ago.

We'll be addressing topics today discussing and focused on women and HIV, so including HIV testing, pregnancy, breastfeeding, U = U or Undetectable = Untransmittable; and also we'll talk about stigma in healthcare settings.

I'll be joined by Heather Ellis and Heather is Positive Women Victoria's communications and engagement coordinator and was diagnosed with HIV in London in 1995. She is a journalist and a published author, and is a mother of three boys, born in 2004 and of twins born in 2007. Heather is going to tell her personal story, and I will talk a little bit about some of the aspects of HIV that come up through our members. I am a journalist and writer myself, and I have been a HIV policy analyst working nationally and with Positive Women Victoria since 2008.

Heather: So I was diagnosed with HIV in London in 1995, and this was after I was travelling through Africa and when I was diagnosed, there were no effective treatments like we have today. So really the doctor said to me, I've got five years before I develop AIDS and die. So I continued my travels overseas travelling through Central Asia and down through China.

By the time I reached Vietnam, I was very unwell, I had AIDS defining illnesses. I returned to Australia, but fortunately then, because this was late 1997, the effective antiretroviral treatments that we have today had been discovered. But I did not know that because I was travelling and this was before the age of Google and the internet and so forth. So got back to Australia, went to the doctor. You know of course I knew I had HIV, went to a HIV support group and they immediately put me into hospital and ten days later I had left hospital. That's how effective the treatments were at that time. I was 32 years old, and within a few months after that I was attending university and studying journalism.

So the treatments, we've got are so effective and they're such a life changer and let people live long, happy, healthy and productive lives and also to be able to have children. I met later, married and had three boys. One first one was in 2004 and then the twins were in 2007. And back then I couldn't have a natural birth. Women today can have a natural birth in the pregnancy. I couldn't breastfeed and I had to have a caesarian section. My three boys were all born HIV negative because I had undetectable viral load. I was on HIV medications which ensure that I have that undetectable viral load, so there's no risk of the the babies contracting HIV during pregnancy or during even during the birthing process.

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But I could not breastfeed back then. There's a lot that has changed. And we'll talk more about breastfeeding as we go on.

I suppose the biggest thing that as a person living with HIV is the stigma, because of the ignorance that's in the community. A lot of people don't know about how effective the treatments are. They still think of HIV as AIDS. And it's not like that at all. And we'll talk more about how effective those treatments are later. That stigma also means that a lot of people will, and even healthcare providers, won't consider testing.

Kirsty: It's probably worth just going into a little bit of information about the epidemiology of HIV in Australia and where we are presently at. So there are about 30,000 people who live with HIV in Australia, and approximately 3500 of these are women. It's estimated that about 10% of those women are actually undiagnosed, so that highlights the importance of testing again. So roughly 12% of all people living with HIV in Australia at the moment are women. And in 2022, there were 85 new diagnoses or notifications, more correctly, amongst women from 555 notifications. In 2023, there were 22 new new notifications of HIV in women in Victoria, so slightly down from 27 reported in 2022, and women accounted for 11% of the total notifications of 198 cases of HIV in Victoria.

So it's important in this context to think about testing, because although most HIV in Australia is still notified amongst gay men or men who have sex with men. We think that the small numbers of women who are diagnosed with HIV relative to this, may in fact lead to the situation where women are often either not tested when they need to be or tested far too late, and therefore can be in the very difficult situation of sort of being diagnosed, for example, during a pregnancy or in some cases many years after the initial infection, where they can have all sorts of problems immunologically and may even, as in some cases be diagnosed with an AIDS related illness.

We think that there are some missed opportunities for testing and in the antenatal setting in particular, it's really important to consider these issues. Obviously, part of antenatal testing and screening for anything is going to involve potentially a sexual history and a history of kind of any other sexually transmittable infections. It's important to stress that this should always involve thinking about HIV. There are various guidelines on this nationally, but they vary a little bit between state in practice. And in Victoria, for example, the wording of the recommendations is a little bit less specific than in New South Wales, and Victoria recommends or strongly recommends that HIV testing is always undertaken in antenatal setting. Whereas in New South Wales it's specified that it is routine to offer this test unless women do not want to have it.

There are also RANZCOG guidelines on this matter and other things, but we believe that it does lead to a situation where, whilst it's not possible to say what percentage of women are screened for HIV antenatally, we do know that probably women are under tested and we are also aware of some concerning cases, such as an example of one of our members who was not tested for HIV during her pregnancy or prior to her pregnancy, and who did not realize that she was living with HIV until her child was diagnosed with HIV after becoming significantly ill and failing to thrive after birth.

So obviously that shouldn't be acceptable in Australia now and that person had said to us that they were surprised to have learnt that HIV wasn't a part of what they were tested for during pregnancy.

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I think that stresses the importance of testing, and one of the messages that can be given in testing now, of course, is that HIV treatment has changed: highly effective, well-tolerated, and it has the virtue of allowing people not only to live a long and kind of ordinary life expectancy, but to be able to do things that women often fear that an HIV diagnosis might preclude, such as having unprotected sexual relations with partners or having children or breastfeeding children.

Heather: The effectiveness of the antiretroviral treatments that have given us this U = U message, Undetectable = Untransmittable. And that means that when somebody is on treatment, has an undetectable viral load, they cannot transmit HIV to their sexual partner when they have unprotected sex. And I know that sounds like something that's amazing and that most people would think, how can that happen? But that's how effective the treatments are. They just stop the replication of the virus. It's still hidden in what they call an HIV reservoir, but it's latent, it's dormant, it's not active, and it's not circulating in the blood, and therefore it's not going to be transmitted sexually to their partner.

I just wanted to talk about testing. When I was talking about my situation, I was healthy when I was tested. I didn't go and have an HIV test because I was unwell. I had an HIV test because I needed to have that to get a three-month Russian visa because that was the next stage of my journey.. And that's why my tests came back positive, because that's why I had the test. And this is why some people might, in this day and age, not require to have an HIV test for many things, but they will feel unwell and then go to their doctor and their doctor will see they're a woman, they don't sort of see them as a high risk group, and then they won't test them until it was too late. And when women or anyone is diagnosed, like with HIV, it's the bad thing about that is the HIV is doing damage to their body. And that HIV reservoir I mentioned is quite large, and that's a source of low level inflammation over time. So having people tested early and on treatment early is really critical so that they can live a long, happy, healthy life.

At the moment I'm taking four pills a day, but I've got some, what they call multidrug resistance, because I've lived with HIV for 30 years, and in the early days I swapped and change medications due to side effects. The antiretrovirals we have today, there are no, if very few side effects, no side effects for what I'm on. Majority of people living with HIV are on one pill a day. There's new clinical trials where there can be one pill a week, that's in the pipeline. There's also what they call long term injectables, so people can have injectable treatment every two months. There's also a twice yearly long term injectable as well that is available for people on with multidrug resistance. Some people also have an issue with adherence with taking pills every day they might forget and then they can build up resistant resistance to that particular antiretroviral.

So that's the great news about anti-retroviral treatments moving into the future. And just wanted to mention just briefly about HIV cure. We have come so far in the past five years, and the big focus now with HIV cure research is to try and attack and remove that HIV reservoir, which is the source of HIV replication, when treatments are stopped. So if say somebody stops taking treatment, they'll have what they call rebound or viral rebound within, say, 2 to 4 weeks and the virus starts replicating again. So they need to get rid of that reservoir. So really promising stuff happening. The big thing at the moment with the effectiveness of the HIV treatments and U=U, which means Undetectable = Untransmittable and enormous effect on also helping to end stigma.

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Kirsty: The evidence for U = U, is strong and clear, and it's internationally accepted and has been indeed the consensus since about 2016. So it's a cornerstone of international and Australian HIV policy. That policy acknowledges that Undetectable = Untransmittable has implications in prevention as well as in care.

So from a prevention point of view, it is clear that it is safe for people who live with HIV to have unprotected sex with their sexual partners. The main cornerstone study of that was a few studies and known as the Partner Study and Partner Two studies and the opposite attract studies. So these looked at condomless sex, conception and sero discordant couples. To summarize the data, over about 2500 male and heterosexual HIV sero discordant couples, one partner having HIV, the other not, and 130,000 episodes of condomless sex. There was zero transmission and no genetically linked HIV transmissions were recorded where the partner with HIV was taking antiretroviral therapy and was virally suppressed.

Now, viral suppression here refers to having an HIV viral load of less than 200 copies per mil in circulating blood, and the evidence for that has been built on over the years and we will talk a little bit about how it applies in other areas as well as including pregnancy and breastfeeding. But the evidence is strong and it's clear, it also supports the evidence for the use of pre-exposure prophylaxis, or PrEP, a cornerstone of HIV prevention in Australia, and also post-exposure prophylaxis, or PEP. We'll talk a little bit more about the relevance of those things in pregnancy and breastfeeding in a moment, but it's important to know that U = U has really changed the basis for what people will think about HIV.

And yet that information has not always flowed effectively into sort of mainstream knowledge. Despite many efforts, there are still many people who don't understand that U = U. And we still continue even to come across healthcare providers who are unaware of that principle or have not explained it well to a person who's being tested. So it's an important message because it makes, especially when you're trying to encourage people to be tested, to let them know that they can be treated, treatment is effective, and if with effective treatment, they will not be able to transmit HIV to sexual partners and they'll be able to safely have children, they're all crucial messages.

Both Heather and I have been involved through the National Association of People Living with HIV and through other agencies in the development of guidance for clinicians and guidance for women living with HIV about breastfeeding.

Heather: Really, we had U = U from as early as 1996, when the new effective antiretroviral treatments were developed, which gave people that undetectable viral load. So it's been around for a long time. It's just that we didn't have the scientific evidence and U = U at this point does not apply to breastfeeding because the scientists and researchers haven't pulled together that evidence, even though that evidence is there, because in African countries where women don't have access in some areas to formula and to clean water, the WHO guidelines recommend that women breastfeed, but these women are on treatment. They have an undetectable viral load and that there's been a lot of studies.

The PROMISE study is one of them, which showed that the risk of the baby contracting HIV from breast milk was 0.3%. So it's not zero, but it's nearly zero. So it's a matter of getting all that data together where, in a few years' time, U = U will apply to breastfeeding.

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When the mother is on antiviral treatment, she's got an undetectable, sustained viral load and she's supported by her health care worker. In Australia we, as Kirsty was saying, we have the guidance for healthcare workers and we've got a resource for women living with HIV so they can be supported by their healthcare worker to breastfeed if they wish.

Kirsty: Like the Australasian Society for HIV medicine and hepatitis medicine, so ASHM as it's known, ASHM recently introduced guidance on this exact issue. And what ASHM said was, whilst acknowledging that there has been no international kind of consensus statement, if you like, based on completed science around U = U as there was for U = U with sexual transmission, nonetheless, they do acknowledge that there is significant evidence from many, many settings about the safety of breastfeeding for women living with HIV and particularly based on some Swiss research and study and state that developed this thing called the Optimal Scenario. So the Optimal Scenario for safe breastfeeding, they said, was that a person obviously been diagnosed, they were treating their HIV and had had a sustained, undetectable viral load prior to and all throughout their pregnancy, and the woman was receiving good, high quality and antenatal healthcare and attending all appointments and adherent to the HIV medicine.

Heather: In addition, as well, the WHO are reviewing their guidelines on breastfeeding as we speak, and those guidelines are due to be released in early 2025. And also, there's an international group, Inform Plus, of researchers, clinicians and community advocates who are working together for a global consensus statement on breastfeeding and that will be released in line with the WHO updated guidelines on breastfeeding, and that will then apply for women living with HIV who want to breastfeed in high resource settings. Because at the moment, WHO do recommend breastfeeding for women in low to middle income countries. But in the high resource countries where people do have access to formula, this is all changing and it's fantastic.

Kirsty: We also think that attitudes amongst clinicians are changing. There is a general consensus that its [breastfeeding] something that can be discussed with women and should be discussed with women, and that for women who do feel very strongly that they wish to breastfeed, which may be for various reasons, sometimes it's cultural reasons, sometimes it's personal or health reasons, sometimes it's because of a fear that not breastfeeding in certain settings will be interpreted as that woman living with HIV, and so therefore is a breach of confidentiality and that's apparently quite common within some of the overseas communities that we work with. I think it's important that clinicians are becoming slowly more used to discussing this with women, and the ASHM guidelines certainly encourage, where women do wish to breastfeed, that this can be supported and discussed and the women supported in their choice, where the optimal scenario applies, and certainly what the guidelines would discourage and we would continue to discourage is any intervention around breastfeeding of the sort that we have seen in the past, for example, where women have been threatened if they choose to breastfeed, that social service agencies will be involved and may in some cases remove babies on the basis of breastfeeding is not safe for the child. So we're moving well beyond those things and there should be no basis for a legal intervention in these cases. However, women need to be supported to make the right choices.

We also want to talk a little bit about the conception of a child, because women will often come to Positive Women with a new diagnosis and their baseline assumption especially if they don't know much about HIV and haven't had much knowledge or experience of it is that they may fear, or even be told that it will not be safe for

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them to have children.

So we want to stress that it is safe to conceive children where one or both partners are living with HIV, where anyone who's positive is taking antiretroviral therapy and viral load is undetectable, and that means that a natural conception is possible for heterosexual couples, and many people choose that option.

Heather: As a woman living with HIV my husband was also positive back in the early 2000s, before U = U, then I probably wouldn't be able to have had a natural conception because the U = U message and data wasn't there, but that wasn't my situation. So I fell pregnant and yes, I was concerned about what would happen to the baby because in a way, an unplanned pregnancy at the time, and I was reassured by my doctor that no baby has been born positive to a woman living with HIV in Australia who is on treatment with an undetectable viral load.

So that was like fantastic for me to hear that information that there was no risk to the baby being born with HIV. But what did happen when I did that pregnancy test at home and I went to a local clinic? I live in a regional town and I said, look, I'm pregnant and I'm living with HIV because I was really concerned. He said to me, well, I recommend that you should have an abortion because one, you're living with HIV and you're a mature age pregnancy, I was 40 at the time.

So this is that was my first real experience of stigma in healthcare settings. I was just shocked by that news. The next day I rang my HIV doctor and I was reassured that everything would be fine. Everything is perfect. There's no risk to the baby. I wasn't too old to have a baby even though I was 40. Women of 40 had babies all the time. But over the years, any stigma I have experienced in my life has always come from a healthcare setting, and this is a common thing that happens to people living with HIV.

For some reason we experience all this stigma in the healthcare setting because of that ignorance, and the healthcare worker being judgmental about who we are, like how we've got HIV. Like the question I often get is how did you get it? You know, it's nothing to do with them. It's none of their business how I contracted HIV. But they even today will always ask that question. And I've had another doctor say to me, oh don't share my toothbrush. I mean, like, why would I share my toothbrush anyway? These kind of things. And other doctors, even just recently like this very year said to me, oh, I thought HIV was cured like Hepatitis C. This ignorance in the healthcare providers, particularly GP clinics, really needs to be addressed. They just don't have any idea.

The other big issue around stigma is that confidentiality. You know, not talking about that the person's HIV status where others can overhear it. And I actually have, this is a really positive experience. I went to a doctor recently. I had to get a referral for one of my boys. He was in the waiting room with me. And the doctor, I also wanted to get a script for another medication, he could see on my chart that I was positive and the medications I was on, but he realized I had my son with me. He didn't mention anything about HIV, which was fantastic. My children or my three boys know I'm living with HIV, so it's not a problem. But I thought, you know, good on you that you know to be confidential. Other doctors might say straight away, “Ah I see you've got HIV” and that could have been in front of my child who doesn't know anything about it. So there's the breach of confidentiality in the health care settings is another big area that people living with HIV fear when they go into to a clinic, especially if it's not an HIV specialist clinic.

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Kirsty: Amongst our membership, we have many examples of the forms that stigma can take, can run from not testing for HIV based on assumptions about a person's sexual history or sexual past, incorrect information given about transmission, which Heather has mentioned. We've had clients who have been told to terminate pregnancies at 36 weeks, and this was very recent. We've had clients told that they can't work with children or indeed touch children as a result of their HIV diagnosis. And again, that was a recent piece of information. We've had multiple reports of people's confidentiality being breached in hospital settings by HIV being discussed in public or out loud. And we've also had quite a number of women who've talked about the judgments and presumptions that are made about their sexual history or behaviour or their assumed use of drugs.

We think there are many, many things that can be done to address HIV stigma in the healthcare setting and, you know, getting incorrect information when you're diagnosed is really a form of stigma. So universally, people can't expect to have same level of knowledge right across the healthcare setting when they're diagnosed or in other settings. And I think that's an important social justice thing to be kind of remedied for both for women and also for heterosexual identified men who do suffer high levels of discrimination within healthcare settings in relation to HIV as well.

I just wanted to briefly mention before we sign off that we wanted to also touch on the issue of what happens after a baby is born to a positive women. So in Australia, as well as viral load testing and other things that will happen at testing wise following birth. The policy at the moment is still for infants to receive what is called post-exposure prophylaxis, usually in the form of either nevirapine or AZT. And there is an established regimen for babies during the first few weeks after their birth. There are some researchers around the world who are exploring whether the evidence for needing to do this is changing. And again, based on U = U. Some people feel that there is a move towards thinking that infant PEP may not remain the practice, using a kind of risk benefit analysis, given the sort of baby's treatment or drugs, is not ideal unless they really need them. And assessing that risk to see if the Optimal Scenario applies, the baby is really not at risk of being born with HIV.

All of the materials that we've talked about here can be found on our website. And the evidence for this information, which you may want to discuss. The main message that we wanted to convey to you today is that antenatal testing for HIV is really important and should be done; that a positive diagnosis does not prevent people from leading a full and rich sexual life and from having children, and that there is a shift to change in practice around the management of both pregnancy and the breastfeeding process and newly born babies. That is all based on the increasing confidence in the science of U = U.
Heather, did you want to say any more final words?

Heather: To be aware of the signals and the indicators that testing is needed. You know, don't just assume that woman in your clinic doesn't need an HIV test. You know, be aware of, like have they traveled to a high risk country? You know, like don't be afraid to ask them about their sexual history. If they've come in and they've complained about a repeated illnesses, don't misjudge the fact that it might be HIV. Now, include that in one of the tests that you do to find out what the problem is. Be aware that HIV testing really is so important, and that early testing and early treatment will really make a huge amount of difference to that person's life, if they can be tested early and then go on treatment.

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Kirsty: Thank you for listening to this podcast. We are positivewomen.org.au

On our website there is information about pregnancy and breastfeeding and more, as well as quite a number of videos of the personal stories of women living with HIV, some of whom discuss their experiences of diagnosis, pregnancy and other relevant topics, so details and links to the resources mentioned in this show are available on this website or for this episode.

We hope that you have gained a greater awareness and are feeling better informed about women and HIV from our discussion on this episode of MOGCAST.

And thank you for listening and goodbye.