

poslink

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DISCLOSURE IN THE FAMILY



*NAMES HAVE BEEN CHANGED AND DO NOT REFLECT THE IMAGES IN THE ARTICLE.

Disclosing your HIV status to the people you love can be daunting. It is important for many people to have someone to share your true self with, someone to be honest with and who someone who can offer support. These people can be partners, friends, family or other people living with HIV.

**Sam: "I was so anxious about telling my dad. He's very traditional and a stiff upper lip sort of guy. I cried. He cried. I'd never seen him cry before so that shocked me. But then he hugged me and told me he loved me, no matter what. That has brought us closer."*

**Nina: "My sister has been a rock for me. Her love and acceptance has given me strength when things get difficult. I need someone who knows the real me."*

When you are a parent it can be even more complicated. Many parents question whether or not they should tell their children that they are living with HIV. The role of a parent of children and teens is to provide support and nurture. The question then becomes, "If I am not seeking emotional support from my children, do I need to disclose my HIV to them?" There is no right or wrong answer to this question. Every family is different. What works for one family or one child may not work for another. Parents are often best placed to know whether telling their children about HIV is right for their family.

Parents take very different approaches to disclosing their HIV status to their children. For some people disclosure is very important to them. They may want to be in control of

personal information or ensure that their children receive accurate and reassuring information. Or they may just want to be completely open with their children and not have to hide information, appointments, medications and the like from their children.

**Sally: "I told Jake when he was about seven. It's been a bit of an evolving conversation as he gets older. He asks new questions. I answer them as best I can. I don't know how much he understands yet but he's been great."*

For others, disclosure can be gradual or just happen incidentally.

**Emily: "I have started to think about telling the girls. I don't know that I'll tell them outright. It's more that I just don't hide it from them. They come to my appointments, everywhere really. I'll just answer the questions as they come up I guess."*

And some parents make the decision not to disclose to their children at all. This may be because they see HIV as a private health issue that doesn't concern their children. Or they may want to shield their children and themselves from stigma and discrimination.

**Andrew: "I have thought long and hard about whether to tell my kids. I just want them to have a regular childhood. I don't want them to worry about me or to have to keep secrets. And I don't want them bullied at school. I might tell them down the track. But for now I'm holding off. There's still ignorance out there."*

If you are considering disclosing your HIV status to your children other parents have found it helpful to consider the following points:

- Use language that is appropriate for their age and stage of development
- Are they under stress at the moment? If so, you might want to wait
- Reassure them that you are looking after yourself, are being well cared for by doctors and that you are healthy
- Be ready to answer questions now and over time
- Consider if you want them to keep your HIV status private. Are they mature enough to understand this?
- Is there someone else they can talk to if they have any concerns? Another parent? A trusted family member or friend?
- You might want to have someone else with you when you talk to your children. This can provide them with reassurance
- Help them find age appropriate resources if they are interested. The internet is full of misinformation about HIV and AIDS that might alarm your children. If you can offer them up to date, accurate information it can help them better understand HIV.

You can also request the booklet, *Disclosing to Your Children* from Living Positive Victoria. If you are considering disclosing your HIV status to your children, or if your child is living with HIV and you are thinking about how you will tell them, speak with one of the Peer Support Officers at Living Positive Victoria. They can provide guidance in making decisions about disclosing to your children and how to support them through the process.

GUESS WHAT KIDS? A STORY OF DISCLOSURE

By Anth McCarthy



“I have this thing. It’s kind of an illness. But don’t worry, I’m okay! I’m not going to get sick...well actually, I could get sick, but I’m not going to die or anything. Okay, you’re right, everyone dies eventually. Anyway, it’s called HIV. Have you heard of it?”

My kids stared blankly at me. That’s pretty much how I opened the conversation with them about me, their dad, living with HIV. Perhaps it wasn’t the most elegant, but I had to start somewhere. Certain practicalities were demanding that I tell them soon so I decided to talk to them at the dinner table.

Before I go any further, I must declare that I’m pro HIV-disclosure and not just to kids. But that wasn’t always the case. I have been living with HIV for a long time and I spent most of that time carefully hiding it. Something changed profoundly for me about a year ago and I decided I wanted to live openly as an HIV positive man. Weird but true. My wife had been encouraging me to take this step for years. We understood that once it was public there would be no going back.

However, I recognise that we are all comfortable with different levels of disclosure. As people living with HIV, we each experience very different constraints and freedoms that are determined by our history, our transmission story, our family and our culture. No one can tell you what to do because you are the preeminent expert on your life, and no one knows your family and children better than you. Even if you plan to keep your status private, I hope my experience helps you weigh the risks against gains of disclosing to your children. One thing is for sure, it’s a complex decision that can’t be rushed.

I knew without a doubt I had to tell my son (11 years old) and daughter (9 years old) in advance of my public disclosure. I could not bear them finding out from another source. I wanted them to hear the truth, my truth, before they were exposed to any stigmatising language or nasty myths about the virus. My plan to announce my status on Facebook took a lot of the stress out of telling my kids. I knew there would be no extra pressure on them to keep it a secret.

My kids had no preconceptions about HIV. They were still simply, and beautifully naive about one of the most socially stigmatised illnesses. They weren’t shocked or scared for me and they did not judge me. In fact, nothing changed about the way they treated me. My daughter, who is always brutally honest, warned me that she might forget. Recently she asked, “Dad, is HIV in families?” I understood her to be asking if she had HIV. I reassured her that she did not have HIV like me, and she happily went back to her colouring.

I want my kids to see me being proactive about my health. My kids have seen me taking pills their whole lives. It must be very normal to them, and I wonder if they believe that their friends’ parents must take lots of pills and have lots of medical appointments too. One thing is for sure, I wanted to frame my status as something that was not shameful or negative so my kids would view people living with HIV, or any chronic illness or disability, as people, not a diagnosis. As people living out their potential, not as having a deficiency. I want them to respect and value all people.

Also, I want to show my kids that it’s okay to be different. Being different adds diversity to the world, and diversity adds value. HIV positive people are valuable because they are different, in the same way that say people with autism are. We HIV folks create diversity and diversity is to be celebrated with pride. When diversity is celebrated, it gives permission for others to be diverse too.

I hope that I have laid a foundation for my kids to talk openly about HIV as their understanding of HIV grows. I have kept HIV in a dark place for long time and now want to help bring it into light. I thought carefully about what was right for me, my partner and my kids. Thankfully it worked out great and I don’t regret it.

VICTORIA'S SEXUAL AND REPRODUCTIVE HEALTH PRIORITIES FOR WOMEN

Having access to quality and affordable sexual and reproductive health care in close proximity is essential for all women. In an effort to improve the health of women, the Victorian Government has recently released its first health strategy and action plan, *The Women's Sexual and Reproductive Health Key Priorities: 2017-2020*.

Good sexual health care and access to reproductive health services is important for women living with HIV (WLHIV) who want to become mothers. Often WLHIV have a number of sexual and reproductive health challenges which can affect their ability to start a family. This includes a higher risk of cervical cancer, early menopause accompanied with more severe symptoms, and since HIV interacts with a number of common sexually transmitted infections (STIs) (e.g. chlamydia, herpes, gonorrhoea and syphilis), this can negatively impact viral loads or CD4 counts. Women living with HIV, or a woman who is the partner of someone living with HIV, wishing to become a mother also need access to current advice about conception, pregnancy, birth and care of the baby after birth.

The hope is that this plan that will improve and better coordinate services for women to use. An extra \$6.6 million in new funding has been made available to ensure that women will be able to get the services they need wherever they live in Victoria. The plan also looks at women's sexual and reproductive health in broader terms including an understanding of the importance of respectful relationships, the impact of family violence on a women's health overall, and the role that stigma and discrimination and gender roles play in poor sexual health. There are many situations where the fear of being stigmatised for seeking testing or treatment for sexual health issues prevents women from accessing testing and treatment which contributes to poorer health outcomes.

The strategy has identified the following four key action areas:

1. Improved knowledge to manage fertility

- Improving women's knowledge about fertility factors that affect their ability to become pregnant.

2. Improved access to reproductive choices

- Offering women better access to affordable, reliable and confidential contraception advice, pregnancy support and termination services
- Better access for women living in rural and regional areas
- Involvement of women in making choices about their sexual and reproductive health.

3. Improved access to health services for women with endometriosis, polycystic ovary syndrome and those going through menopause

- Improved access to early diagnosis and treatment of reproductive health conditions that are often hidden such as endometriosis and polycystic ovary syndrome
- Better management of the effects of menopause
- Support to improve the social participation of these women.



4. Better access to culturally safe services for testing, treatment and support regardless of cultural, gender and sexual identity, ethnicity, age, disability or place of residence

- Support to reduce STIs
- Greater attention on prevention efforts for women at risk of sexual health issues.

Although the plan is not specific to services for WLHIV, many of the strategies included in the plan will hopefully improve access to services that are essential for WLHIV. The plan for increased training for health care staff will hopefully reduce HIV related stigma and discrimination and improve the experience for women accessing HIV and sexual and reproductive health services.

Women living with HIV, like all women, need access to affordable and accessible sexual and reproductive healthcare that is delivered by knowledgeable staff who treat them with respect in an environment free from stigma and discrimination. Although sexual and reproductive health concerns are most relevant throughout a woman's reproductive years, it is important that women receive good care throughout their life, into menopause and beyond. *The Women's Sexual and Reproductive Health Key Priorities: 2017-2020* is an important first step in the right direction.

For more detailed information on *The Women's Sexual and Reproductive Health Key Priorities: 2017-2020* visit <https://www2.health.vic.gov.au/>

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