



| Disclosure & Discrimination |

Disclosure & Discrimination

“I am an HIV activist, facilitator, trainer and community-based researcher. I was diagnosed with HIV over twenty years ago and it was the most shattering news I could have faced. In those days I was told that I had a life-threatening condition and I was going to be dead in five to eight years’ time. I had a son who was only two years old and I thought that I might not see him finish primary school. Now he’s about to finish university so that’s rather joyous for me.

Shortly after I was diagnosed, I contacted a peer support group and that was incredibly helpful. I also got some counselling to deal with the diagnosis because my self-esteem was completely gone.

When I was first diagnosed the nurse gave me some good advice. She told me that I didn’t need to tell anybody else unless I wanted to. I told my brother straight away and he was great. It took me months before I could tell friends and they were all okay. About a year later I had an accident and a doctor was called to the scene. I was semiconscious in a pool of blood so I said to her: “Before you touch me I just want to let you know that I’ve got HIV”. She backed away and refused to treat me. She just left me there with open wounds. Although I had been terrified

about what people might think about me having HIV and terrified about any discrimination my son might face, the only discrimination I have ever faced is from health care workers. Not from people who work in the HIV sector, they are true angels but from people who don’t understand HIV. I’ve been refused treatment by dentists. Once when I was going to have a surgical procedure the doctor asked me as I was going under anaesthetic: “A druggie are we?”

I began to speak out to show the face of HIV. At first I spoke within the health sector to help reduce the stigma we face. I think it’s particularly important for people with HIV to speak to young people. People are so afraid to talk to young people about sex because they think they’ll go and have sex. But there’s good evidence that educating young people about sex before they become sexually active is perhaps the most valuable thing you can do, in terms of their life skills and their future. I look at how and why young people trust their partners. The issue of trust is very difficult, particularly for women because we often don’t have the confidence to negotiate safe sex and I think it’s very challenging in long-term relationships.

In 1999, my health was going down very quickly and I had almost no immune system left. I started taking antiretroviral medications; they are miracle drugs. Now I embrace my toxic drugs because I was very lucky. I didn’t have any side effects and I’ve led a much fuller life over the decade or more since starting meds than in the decade before that. The drugs enabled me to embrace life again and to realise that HIV is not a death sentence. Providing I take my medication every day, I can lead a long and healthy life with HIV.

My HIV status defined me before I started antiretroviral treatment and before I went public in the media these two things happened about the same time. Curiously, since I’ve gone public and since I started taking antiretrovirals, my HIV status is no longer so important. Even though I work in HIV all the time, it doesn’t define me any longer.

So it seems HIV is just a stage in what appears to be a long, and hopefully even longer, life.”

My voice is powerful

Disclosure

Most of us are terrified of disclosing our HIV status to the world. We are afraid that we will be viewed differently to other people. It doesn't matter if we were diagnosed decades ago or months ago, each of us experiences some fear about disclosing our HIV status to others. For many of us, it is the most frightening challenge we face, whether we are disclosing to health care workers, to family members, to potential sexual partners, to our children, to work colleagues or to friends.

Disclosure is not a one-off event but something we continually have to negotiate as we meet people who have no reason to associate a healthy looking woman with HIV. Because we fear the possible consequences of disclosing our status, most of us tend to keep it tightly to ourselves. This adds a huge burden of secrecy to our lives.



Those who mind don't matter and those who matter, don't mind

Friends

A few of us told the world about our HIV shortly after we received our diagnosis and it backfired. We found that some friends were not as trustworthy as we had hoped. We faced negative reactions and we lived to regret disclosing. Some of us have told nobody because we are so afraid of the reaction. Many of us share our status with only a few close, supportive friends or family members.

"Always be honest, it's the best way."

"No way! No. Don't tell. Absolutely Not. Haven't told anyone - afraid of the outcome."

"I had to tell someone at point of diagnosis: my best friend. She was supportive. My next disclosure to a friend I'd trusted rejected me. I have put up a wall, isolated myself, kept the virus secret."

"I have found it easier at times to simply keep my own counsel and my own company. This I am aware isn't healthy."

Several of us feel that HIV has coloured our ability to make friends. With time, most of us learn who our true friends are, who we can trust to share our HIV status, and when to keep quiet.

"Finding out I was HIV-positive at 19 showed me who was just there for the good times."

"My friend cared and wanted to know what was wrong. I told him. He wrapped his arms around me and said you can talk to me."

For each of us who has faced rejection or stigma, others have had good experiences. Most of us who have disclosed to friends have found them supportive.

I am who I am

Family

Disclosing to family members is very hard. We feel guilty that we will disappoint them, cause them pain, wreck their lives. While siblings are often very supportive, sometimes our parents' reactions can be harsh. They act out of anger, blaming and rejecting us. Mostly our parents are very supportive, even if they don't know how to show it.

"I haven't disclosed to anyone other than my son, but his wife wouldn't let me kiss the kids."

"My mother found out I was HIV-positive after twelve years. All she said to me was, 'I know: when you're ready to talk to me about it, I'm here.' It was the best thing she could have said."

I am a good person and deserve to be loved

Partners

We are afraid to tell sexual partners that we have HIV because we fear rejection. We get anxious and lose any confidence we may have had. Most of us would prefer to disclose our status if somebody gets close to us but it feels so difficult at times. Usually we choose to wait until we know the person really well. Sometimes our status is disclosed to partners without our consent. Reactions vary enormously, but some of us have forged new relationships, told our sexual partners that we are HIV-positive and it has all been okay.

"Always a tricky one. Do I tell the person straight out and risk rejection? Do I wait and then hurt them by not being open and honest? I like to get disclosure over with. If someone rejects me 'cause of HIV then I reject them. I have nothing to feel ashamed about. If the person loves you, HIV won't matter."

"My partner at the time wanted to run a mile, but he thought that would not be helping me or him. Still together now after 15 years with three beautiful children."

"After weeks of me convinced that this man would run as far and as fast as he could, he wanted to marry me and have children. He barely reacted at all and still very much wanted to go ahead."

Don't hold back who you are - Be yourself

Children

As mothers, most of us worry greatly about whether or not to tell our children about our HIV status. Most of us have not yet disclosed our status to them. We are afraid that they are too young, not ready, that it will be a heavy burden on them, that it will have negative repercussions, ruin their lives or change the relationship we have with them.

"I don't want to have to do this if I can get out of it."

Many of us don't know how to tell our children. Unless they grow up knowing about our status from a very early age, how to approach disclosure needs careful consideration. Some of us feel we should make sure there is somebody there for them if they need someone to talk to after our disclosure.

"Telling my son was a series of little disclosures, it wasn't easy. I think he worries about my health."

"Confusing. What are appropriate, age-related questions, how to answer?"

"I waited until I could ask people who had been through the same thing, what their experiences had been. I felt sorry for my son that he didn't have the parents I wanted him to have. I told him when he was four because I wanted him to understand that there were reasons why I couldn't do certain things that other parents could. There was a reason why he lived differently. I told him we had a bug in our system that made us feel very tired and we needed more rest and sometimes it made us sick. He's grown up in the HIV community: it's part of his life, as it is mine."

Most of us who disclose to our children find that despite our fear of the consequences, the results are positive.

"Found it easy. Kids are great at understanding, without stress."

"First thing I did was tell my son. He was wonderful. He wanted to kill the man who gave it to me."

"My child grew up knowing I was HIV-positive so I never had the problem of disclosing."



My HIV status is entirely compatible with living an active, productive and fulfilling life

Work

Wherever we don't need to disclose our HIV status we tend not to. Most of us are adamant that we would not disclose in the workplace because it is not necessary. Those of us who work in the HIV sector, on the other hand, have no problem in disclosing our status at work if we choose to, and we feel that it provides us with a strong connection to our community.

"Never told anyone I worked with. Why do they need to know?"

"I'm lucky, everyone knows I have HIV and it's no big deal."

If you feel worse after you leave a health care professional then change that health care worker

Health sector

Within the health sector our HIV status is most likely to be known or disclosed. Most of us have had very good experiences with health care workers, especially within the HIV sector. We have found doctors and nurses who are helpful, compassionate and caring, who understand us, provide us with information, connect us to other services in the community, and give us emotional support.

"Some of them are brilliant, true angels, particularly those I've encountered who work in the sector."

"Doctors helped save my life, but now I know to take responsibility for my own health."

Unfortunately, most of us have also faced HIV-related discrimination at some time, from health care providers who are ignorant, judgmental, arrogant and lacking compassion. Most of us are frequently asked by health care workers: "How did you get it?", perhaps because we are women in a country that has a predominantly gay epidemic. The question makes us feel uncomfortable. We know it is inappropriate and there is never a simple answer because we know a value judgment is attached to the question.

"There are no guilty or innocent victims and if it doesn't matter to me why should it be such an issue for others?"

"I ask the health professional if 'how I got it' is relevant to my care. Otherwise I ignore the question."



We face negative experiences ranging from non-caring attitudes and insults to traumatic episodes. Sometimes we are placed last on surgical theatre lists and sometimes we are refused treatment. Many of us live with ongoing fear of discrimination by health care workers who have no understanding of working with clients who are HIV-positive.

“During my twenty years of living with HIV I have been refused medical services. I have been treated as something that is untouchable. I have had my sexual activities questioned and judged when I have been in a long-term relationship. It has been assumed that I am a drug taker and promiscuous. And yet without the care I receive in Australia by compassionate people I would not have the wellbeing I have today.”

“I was fairly newly diagnosed, keeping HIV secret. I had a major tooth extraction and told to rest. I had two school age kids, caring on my own. Around midnight, I ended up in emergency hospital needing six stitches. I was so fearful of them treating me differently. They did. I was made to feel like I deliberately bled. I kept hoping it would stop bleeding, but it would not clot. Alone with my kids, I had no adult or peer I could use as a sounding board. I avoided dentists for a long time until I had overwhelming tooth and gum pain. There’s nothing trivial about treatment. It is serious and can rob you of your mental, physical and emotional health.”

Our experiences with health care professionals are up and down. Those of us who have faced stigma or discrimination are subsequently fearful and distrustful when we need to utilise health services in the future. When we are unwell, we don’t have the resilience to deal with discrimination and advocate for ourselves. We don’t have the strength to point out that the concept of standard precautions is simple: treat all clients in the same manner. Discrimination makes us isolate ourselves further so we continue to live with the burden of secrecy. Some of us are able to laugh it off; others feel angry at the discrimination we face.

“I disclose when I feel safe. When I’m sick, the last thing I want to do is deal with people discriminating, judging and assuming. I don’t want to educate others when I’m not well.”

“In over 15 years of being HIV-positive, I must admit that 50 percent of my interactions with services has been fruitful and productive, due largely to my assertive nature. Sadly, the other 50 percent has been less than successful. Ignorance and fear have always been the underlying issue. My mental health has been left up to me to deal with, which is unacceptable when you think about it. When interactions have been negative, I have generally taken it upon myself to educate and inform.”

“Being treated badly by doctors in the past means that I am more guarded now.”

Educate yourself, be informed and keep up to date

Pregnancy

Some of us who are pregnant or want to get pregnant face negative attitudes from medical professionals who themselves need to be educated about our right to have children and how we can do so safely and with dignity and respect.

“When I was pregnant with my youngest child, my doctor decided to walk with me to the nurse’s station. He stood in the doorway and announced, in a raised voice, ‘I need to let you know this woman has HIV’. Not only did all the nurses stop and turn, so did all the patients in the room and those queuing outside. I was only relieved that my eight-year-old who was with me didn’t realise what was said. I felt about a quarter inch tall.”

“The obstetrician jumped away from me and told me he couldn’t treat me. I felt that I was too filthy and unworthy to get medical treatment. When I was in hospital waiting to give birth, one of the nurses didn’t look at me or talk to me for her entire shift. When I asked to go to the toilet, she told me to squat on the bed and use a tray (very difficult being heavily pregnant). When I asked for a tissue to wipe myself (I was attached to a baby monitor), she told me to get it myself.”

Fortunately not all of us who decide to go ahead with a pregnancy are treated badly. Some of us have been encouraged in our decision and reassured that everyone has the right to choose, regardless of being HIV-positive, whether to have a child or not.

“My doctor was helpful as he told me that it wasn’t a death sentence and I would still be able to have a baby. He said, ‘You have the right to have a child’. That was very affirming.”

“No one should decide for you if you want to have a baby. There are ways to minimise transfer from both dad and mum. My baby is living joyful proof.”

*Healing begins when someone bears witness -
share your story, talk about HIV*

Public disclosure

Going public about living with HIV can be a truly frightening experience and also one of the most rewarding. It lifts the burden of secrecy that many of us take on when we are diagnosed. It is a relief that we no longer have to hide that part of ourselves that has had such an impact on our lives.

“Comfortable, confident, part of who I am. I speak with pride.”

Some of us who do public talks in settings such as schools, do not do media interviews because we want to protect our children or parents from any possible negative repercussions. Nobody should ever go public about their HIV status unless they want to and have good support, and their housing and livelihood are not threatened by doing so.



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