



| Diagnosis |

*You are not alone.  
You are not the only woman living with HIV.  
We belong to a family of tens of millions.  
Over two thousand of us are living in Australia.*

## Diagnosis

“I am a proud woman living with HIV.

I grew up in a large loving family in a small country town. I moved to Melbourne in 1985 following the man of my dreams and along with that, a fairy-tale life that most girls have when in love. I gave birth to my son in 1989 and my daughter in 1990. It was during this time signs appeared that my relationship with my partner was under stress but it wasn't until I became sick that the truth came out. In 1994 I was diagnosed HIV-positive. Today, I can reflect on my journey of living with HIV.

My HIV diagnosis brought fear, discrimination and stigma. This mind space did not come from those close to me but from within me. The more I learnt about HIV I found I was more forgiving of myself. Every day was like running a marathon. I was now a single mum struggling to bring up two children, fighting a virus that wanted to take my life and dealing with toxic HIV medication, until finally I was diagnosed with an AIDS-defining illness in 1999. This did not stop me but made me more determined to live.

In 2001, I decided to do public speaking because at the time of my diagnosis I felt very naïve regarding HIV. I thought my life was safe from the risks of catching this virus and yet here I was. It had happened to me. I worried constantly that my children would suffer because of something that was inflicted upon me and yet I felt this incredible need to educate the wider community. Being a mum of two children had a lot to do with this. I found it important to stand up and not be a victim of this virus. I needed to talk - not only about HIV but also issues around safer sex and prevention. I needed to teach communities so that fear does not become stigma and discrimination. This is very important to me. I have found that this has not only helped me, but also my children.

Speaking publicly is a very positive and empowering experience. It has improved my confidence and enabled me to challenge myself and has opened up many opportunities I may never have had.

Today my life is better than I would ever have imagined it could be. My children have grown into well-adjusted supportive and loving young adults. I have also found happiness in a relationship with a very nurturing, good and honest man.

But that's a whole new and different story.”



*I will not let my HIV diagnosis hold me back -  
I am more than my virus*

## The Day that Changed My Life

When we are diagnosed as HIV-positive, we feel overwhelmed by a range of intense emotions. We feel shocked, afraid and isolated. Life as we knew it is changed forever. We suddenly see ourselves as different from the person we were before our diagnosis and our feeling of self-worth is affected as a result. For many of us, the horror of our HIV diagnosis feels unreal and we are in a suspended state of disbelief.

Some of us feel that it is the end of our world. We feel devastated and some of us even consider suicide. We ask ourselves questions that nobody can answer: Why me? Who will love me now? How long do I have to live? What am I going to tell people? What did I do to deserve this? Can I still have children?

Our head swarms with terrible images of poisonous, tainted blood and a slow and painful death. We feel angry, distressed, empty, wrong, confused, finished. We are enveloped by anxiety, fear and secrecy. We imagine we will never again have a partner, children, a future.

*“Not knowing, nowhere to turn, very alone, confronting.”*

*“I felt it was the biggest challenge I could ever face. Not only was I being told I had a life-threatening disease, I also knew it carried so much stigma and taboo.”*

*“Octopus...there are no areas its tentacles do not reach!”*

*“Totally blew my world apart. As time goes by you do adjust somewhat.”*

Regardless of why we got tested and how prepared we thought we were for the result, regardless of our differences, it takes a long time to regain a sense of self and where we are in this world. For some time we are on “sensory overload”: there is too much information and also not enough.

For those of us diagnosed early in the epidemic, HIV meant a death sentence. Since then, antiretroviral medication has stopped what was an inevitable progression from HIV to AIDS and thus death. We now know we can live long and healthy lives with HIV. Yet women diagnosed with HIV today still take on much of the fear and stigma that has been forever associated with HIV.

*“Through engaging with the women’s group I have learnt to love and hate ‘Alvin’. It has helped me to name this wicked child that lives inside my body. Heaven forbid I have ‘AIDS’. No, I have ‘Alvin’ with me. I have accepted ‘Alvin’ even though I have carefully and decisively not disclosed to most people in my life. How come I am no longer overwhelmed by ‘Alvin’? Briefly, occasionally, I still am but I have sought out people to talk to about it - women’s groups, psychologists, doctors, internet forums. My partner gets angry and feels his life is wasted because of being positive. I don’t think like that. I need to keep stronger for my children, and for myself. It helps to make plans, keep busy and not to give up on yourself. I don’t like living with ‘Alvin’ but it isn’t all bad and with support of others, I can cope.”*

*“HIV is different now. We were told that we would only have a few months or years to live. Now newly diagnosed women need to plan to have a long and productive life.”*

*“I didn’t know that I had commenced a journey but today I know I have. It changes and evolves. The initial honeymoon or ‘horror-moon’ period passes.”*

*You can't be stigmatised if you feel good about yourself*

## Stigma

At some point and to some extent all of us feel a sense of stigma in relation to our HIV diagnosis. Many of us feel we will be treated differently if people know we are HIV-positive. Depending on how we contracted HIV, we feel we will be judged as being better or worse than others: perhaps tainted as a loose woman, a slut, or a junkie. If we have experienced stigma, we try and avoid situations where it may happen again.

*"I know many people judge whether I was unfortunate or just irresponsible."*

*"What I've realised over the years, is that a lot of the stigma is self-perceived. Yes, there still is stigma attached to being HIV-positive, but how much do I want to buy into that?"*



At a personal level, we are often our own worst enemy. We take on a great deal of the stigma associated with the virus and internalise it. Sometimes the stigma is much harder to deal with than the physical implications of being HIV-positive. For some of us this self-stigma manifests as overwhelming feelings of shame or irrational feelings of guilt. We can be so cruel and say very hurtful things to ourselves.

*"I am filthy, I am dirty, I am damaged, I am dangerous."*

Shame and stigma are a big part of trying to cope with HIV and we need to try and work through it. Over time, feelings of stigma do lessen.

*"Strong self-esteem is the answer. If you're confident in your love of yourself, stigma can't hurt you."*

*"It has been lovely taking off that heavy cloak."*

*It is a personal journey but try to stay connected with other people*

## Isolation

Most of us experience a sense of extreme isolation after our HIV-positive diagnosis. We move into a dark and difficult place for months or even years. Our internal stigma causes us to pull away and withdraw from people. We feel no one will understand us and nobody will want us. We try to keep it a secret from everyone so we have no one to talk to about it. At times it's all too hard and we disconnect from everyone around us. We feel very lonely, and this in itself eats away at us.

*"My aloneness envelops me often. I feel quite isolated in the world."*

*"Isolation for me is so much a part of the early days of HIV. Sometimes we can choose to isolate because we think we are lesser than we are. That's not the truth. You're not the only positive woman out there. We belong to a family of tens of millions. Even if you feel or think you are alone, we are all out there living the best we can with HIV. Sometimes it is comforting to wrap yourself in the blanket of isolation."*

Some of us grow accustomed to the isolation and we seek it out as a place to enjoy time alone to reflect on life choices, without having people telling us what to do.

*"My head is the space I retreat to: where I find confidence, memories and the strength to look forward to everyday, the future and living a happy life."*



*I am brave and resilient*

## Grief and loss

Each of us faces grief and loss in some way as a result of HIV. We grieve over the loss of the life we believed we were going to lead: the loss of our sexuality; of opportunities to forge new relationships and find a partner or create a family; of the chance to study or to carve out a career and earn money. All of us fear and grieve the potential loss of our health. Some of us have lost our husbands, partners or children to HIV, and some of us have lost friends and colleagues. Sometimes we wonder why we are still here.

*"Grief and loss are a part of my life... When you find out you are positive you grieve and believe that you have lost your life and all possibilities that come with it. As I have lived into my second decade I have grieved the positive people that I have loved and lost. I'm amazed at how many funerals I had to go to in such a short space of time. I've lost so much from each and every one who's died and yet gained so much from the lives they have lived."*

*"I'm still grieving: it's a journey for me, it's not as heavy as it once was but it's with me every day."*



*I continue to get stronger all the time*

## Emotional health

Most of us plunge into a downward spiral when we are diagnosed with HIV. Feelings of stigma, isolation and loss can contribute to poor mental health, which impacts on our physical health. Although most of us recognise how important it is to maintain a positive mindset, we often struggle to do so. Some of us lose a sense of who we are and start to question our identity.

*“Somewhere between starting treatment and menopause, I lost my identity. I forgot who I was, what I enjoyed, what makes me laugh, cry, be happy or sad. Was it accelerated ageing, early menopause or the whole lot?”*

Not all women living with HIV experience depression, but HIV does throw us into a dark void that we would prefer not to visit. For some of us depression was with us before HIV and testing positive certainly compounds the condition. Our emotions are cyclical and we go through highs and lows. Gloom, melancholy or despair can sometimes creep up on us when we least expect it. We learn how to manage it in different ways as best as possible.

*“I was so depressed for so long. I had such a low self-image. I learnt a trick to make myself feel better: make an effort, especially when you feel low. Dress up, put on a bit of make-up. It was just like a mask: when I put it on I felt different. This made me feel better about myself. I became a different person.”*

HIV sends us on a roller coaster of emotions. Overall, our emotional lows decrease with time, but they still sneak up on us periodically. Keeping busy and the passage of time help many of us through the initial challenges that our diagnosis brings. For some of us day-to-day routines are necessary to keep our spirits up; for others it's finding something to look forward to. And for those of us with children, they usually snap us out of our negative mindset eventually. Connecting with other HIV positive women is very valuable and important. Peers allow us to realise that we are not alone. We understand how best to support each other.

*“It's getting better through more contacts with other positive people as time goes by.”*

*“No one can comprehend how it feels apart from other HIV-positive women.”*



**PositiveWomen**

*Support and advocacy for women living with HIV*

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